

AGING WELL:

USER CENTRED PRINCIPLES FOR AGING IN COMMUNITY

Jen Recknagel

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Submitted to OCAD University in partial fulfillment of the requirements for the degree of Master of Design in Strategic Foresight & Innovation.

Toronto, Ontario, Canada

April 2018

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ABSTRACT

Aging Well is an exploratory research project aimed at uncovering grassroots models of seniors' supportive living that are emerging across Canada and the United States. The research takes a lead user approach to uncover and describe new models of senior living and supportive care that are developing to address the issues of aging in place and seniors social isolation.

Ethnographic case studies of four grassroots initiatives are discussed, including Homesharing, Senior Co-housing, Naturally Occurring Retirement Communities with Social Service Program (NORC-SSP), and Virtual Villages. Each case study includes audio documentaries of user experiences and photographic documentation of community life. A distillation of key elemental practices by user innovators, along with corresponding design principles for aging well in community is offered. This project is intended to inform the future development of seniors' supportive living initiatives.

ACKNOWLEDGEMENTS

To my OpenLab colleagues for the inspiration and determination that you show up with every day.

Particularly Tai Hyunh, Lora Appel, Eva Appel and Cheryl Tsui, who were especially helpful in finishing this project.

To my friends Sara and Dan for providing shelter from the storm. And to my dearest Tanya, for providing needed perspective and grounding.

To Christine McMillan and Arlene Noble for being my Chief Elders in Office, and for opening me up to the possibilities of creating change at any age.

To my primary advisor, Helen Kerr, for sticking it out with me all these years.

And to my family for always been there.

Jen Recknagel, April 2018

This research was supported by the Ontario Trillium Foundation



An agency of the Government of Ontario.
Un organisme du gouvernement de l'Ontario.

TABLE OF CONTENTS

PREFACE / *page 3*

CONTEXT / *page 4*

PROJECT OVERVIEW / *page 7*

THE LEAD USER APPROACH / *page 8*

RESEARCH PROCESS / *page 10*

FINDINGS: GRASSROOTS MODELS OF SENIOR LIVING / *page 15*

HOMESHARING / WOMEN'S HOUSING INITIATIVE MANITOBA page 16

SENIOR COHOUSING / HARBOURSIDE COHOUSING page 36

NORC-SSP / CO-OP VILLAGE page 60

VIRTUAL VILLAGES / VERDE VALLEY CAREGIVERS COALITION page 79

REFLECTION / *page 99*

KEY INSIGHTS AND EMERGENT PRINCIPLES / *page 104*

NEXT STEP / FUTURE RESEARCH / *page 108*

BIBLIOGRAPHY / *page 109*

APPENDICES / *page 113*



1. KATHERINE AT WOMEN'S HOUSING INITIATIVE MANITOBA / 2. BETTY DAVIS AT VERDE VALLEY CAREGIVERS
3. NEAL SHWARTZ, CO-OP VILLAGE NORC / 4. HELEN BAKER, CO-OP VILLAGE NORC

LIST OF TABLES

Table 1.	Research Process Overview p.27
Table 2.	Models Comparison P. 82

LIST OF FIGURES AND ILLUSTRATIONS

Figure 1.	Katherine at Women's Housing Initiative Manitoba p. vii
Figure 2.	Betty Davis at Verde Valley Caregivers p. vii
Figure 3.	Neal Schwartz, Co-op Village NORC p. vii
Figure 4	Helen Baker, Co-op Village NORC p. vii
Figure 5	Bev Suek at WHIM p. 19
Figure 6	Exterior of WHIM p. 22 + 23
Figure 7	Katherine in her room p. 26
Figure 8	Bev in the living room at WHIM p. 27
Figure 9	Lynda cooking a communal dinner p. 30
Figure 10	Lynda in the shared kitchen p. 31
Figure 11	Lourdes studying for exams in her office. She has recently gone back to university p. 32
Figure 12	Lourdes, 66, the newest member of WHIM, sharing a laugh with Bev p.32
Figure 13	Harbourside Cohousing p. 40
Figure 14	The exterior of Harbourside p. 44 + 45
Figure 15	Harboursiders doing yoga p. 48
Figure 16	Warren doing this dishes p. 49
Figure 17	David Hannis p. 52
Figure 18	Binoculars p. 53
Figure 19	Margaret Critchlow p.54
Figure 20	Bob Stamp p.55
Figure 21	Arlene Stamp p.55
Figure 22	Community planning board p. 56
Figure 23	Residents clearing beach p.57
Figure 24	Exterior Co-op Village NORC p.64
Figure 25	Lower East Side, Manhattan p.67 + 68
Figure 26	Don West p. 71
Figure 27	Tenement buildings, Lower East Side p. 72
Figure 28	Ned Lustbader on a house call p. 73 + 74
Figure 29	Mr. Hyman Segal, 100 p. 74
Figure 30	Neal Goldstein p. 75
Figure 31	Helen Baker p. 76
Figure 32	Arizona highway p. 83
Figure 33	The Greater Verde Valley, Arizona p. 86 + 87
Figure 34	Kim Meller p. 90
Figure 35	Tom Brand and Betty Davis in doctor's waiting room p. 91
Figure 36	Arizona highway 2 p. 92 + 93
Figure 37	Betty Davis p.93
Figure 38	Betty Walker p.94
Figure 39	Valloy on a friendly visit p. 95

ACCOMPANYING MATERIAL

The following accompanying material is available upon request from the OCAD University Library:

1. Audio documentary with Beverly Suak at Women's Housing Initiative Manitoba
The file name of this sound file is "HOMESHARING_Bev.aif"
2. Audio documentary with Katherine Lowery at Women's Housing Initiative Manitoba
The file name of this sound file is "HOMESHARING_Katherine.aif"
3. Audio documentary with Margaret Critlow at Harbourside Cohousing
The file name of this sound file is "COHOUSING_Margaret.aif"
4. Audio documentary with Bob and Arlene Stamp at Harbourside Cohousing
The file name of this sound file is "HOMESHARING_Bev.AIF"
5. Audio documentary with Helen Baker at Co-op Village NORC
The file name of this sound file is "NORC_Helen.aif"
6. Audio documentary with Betty Davis at Verde Valley Caregivers Coalition
The file name of this sound file is "VIRTUAL VILLAGE_Betty.aif"

Anyone requesting the material may view it in the OCAD U Library or pay to have it copied for personal use.

WHAT IF THERE WAS ANOTHER WAY TO GROW OLD AT HOME?

"Statistically, one of us will die in the next 10 years. Then, statistically, the other will remain in this big house for another 10 years, increasingly dependent on our children and the government.

Then one day, the children will become impatient...and they'll find a more institutional setting for us where we'll have 'company, support, and attention', but it won't necessarily be what we want. And by that time, we'll be too weak and tired of burdening our children to object to whatever they come up with. And we'll live out our lives there, dependent and unhappy."

- Charles Durrett,
The Senior Cohousing Handbook: A Community Approach to Independent Living, 2009

Preface

Old age happens fast. Well, actually it happens gradually, over an extended period of time. But the feeling of old age – of the body misbehaving and not doing what you want it to anymore; of aching and creaking as a near constant state – happens fast. Or so I am told. Few are prepared for the changes old age brings into daily life: from mobility and cognitive changes, to financial and social realities.

My interest in the experience of aging began around the time that I started working at UHN OpenLab, a health innovation lab based at Toronto General Hospital. Previous to this, I had worked as a documentary producer, and was primarily interested in capturing personal experiences, and turning them into stories that highlight some facet of our collective experience. The big idea was that by shedding light on our humanity, storytelling could be a mechanism for consciousness-raising and ultimately, social change. In 2011, when I was called to the world of innovation and design, I had thought that I was leaving this all behind. I quickly realized this was not the case.

I came to understand that listening deeply to personal experiences, or in this case, patient experiences, can be a valuable part of improving care. The same tools of observation, semi-structured interviewing, and narrative that I honed in my life as a documentary producer are equally as valuable in the world of design and health care. To deeply understand user experience, is to hear unmet and potentially unexpressed needs. These insights and ‘pain points’ are akin to ‘story points’, which can be used as scaffolding to develop a useful product: whether services, tools or films. It is my personal experience that it is in both the process of capture, with its heightened sense of intimacy and reflection, and in the process of editing, with its repeated viewing of interview artefacts, that patterns and significance start to emerge.

Documentary filmmaking and other narrative-based forms of ‘sensemaking’, have deeply informed my approach to design. And much like my first impulse, storytelling can be used to help inspire change in a design context. Bas Raijmakers posits in his work on design documentaries that they are meant to “*inform and inspire design*” and that it is in the “*incidental details that might or might not be important for design...activities, homes, aesthetic tastes, ways of expression... that [research] ‘comes alive’*.” (Raijmakers, et al, 2006) Stories are sticky – they wedge themselves into the brain of an audience and take root in a much different way than generic research reports. (Denning, p. xvii) They act as little pieces of reflexive design that allow audiences to live in the creases of users’ words, and imagine what it might be like to be them. Or in other words, to build empathy – which in itself can be seen as a tool of change. (Sander, p.20)

For this project, a research-through-storytelling approach was chosen in part for the reasons outlined above, but also because they meet the subject of the research in a unique way. In our society, we often do not bother asking seniors what they want. We talk over and through them; thinking we know best. This project attempts to do the exact opposite. It sets about trying to understand the experience of aging in place and senior social isolation by interviewing seniors as experts, and studying what they themselves are building to solve those problems.

More intriguing for me, and perhaps unexpected, is the cultural shift that seems to be underway. Seniors today are living longer, and on average, are much healthier than previous generations. The stories that are captured herein paint a different picture of what growing old could look like if seniors were given the space to redefine it for themselves. Are we going to give them the respect of listening?

Context

Over the next two decades, the number of seniors living in Ontario is set to increase dramatically. Currently, seniors over 65 years old represent 16.4% of the province's overall population. That number is expected to double by 2041 as the boomer generation comes of age. (Ontario Seniors Strategy 2017, p. 9)

At the same time, Canadians are living longer. Census data from 2016 shows that seniors aged 85 years and older are the fastest growing population group in Canada; increasing at a rate four times faster than the overall Canadian population. If population rates continue, it is estimated that aging alone will add \$2 billion per year to health spending in Canada. (CIHI 2017)

While the full impact of this shift is still being revealed, in health care, this demographic imperative is adding pressure to find new ways to deliver efficient and effective means of providing care to seniors. This pressure has resulted in more calls for increasing care delivery in the home.

Aging in Place

Seniors want to live independently. A reported 85% of Canadians want to 'age in place,' meaning in their own home or their community of choice while maintaining a sense of community involvement, independence, and dignity. (National Seniors Council, 2014) For many people, it simply means staying out of institutional care.

Long-term care, with its institutional setting and lack of control over personal decision-making, has been criticized for taking away one of the fundamental aspects of being human: self-determination. (Beckingham & Watt, 1995) These institutions have been criticized for creating a one-size fit's all approach to living that dictates when you sleep when you eat, and what social and recreational activities are available. (UHN OpenLab, Aging Suit)

For this research project, seniors across the study population repeatedly reported that going into long-term care or a nursing home is one of their greatest fears. Some acknowledged that one day it might be necessary, but up until that point, they wanted to be making decisions for themselves.

"You have no decisions to make except maybe what you want to eat. You have nowhere to go and nothing to do. And nothing new to learn."

– Margaret, Harbourside Cohousing

It has been estimated that almost one in three people currently in long-term care could have delayed or avoided admission to residential care if they had adequate community-based supports. Long-term institutional care is expensive. (CIHI, 2017) In Ontario, it costs the government between \$130-\$150 a day to care for someone in long-term care. (Ontario Long Term Care Association, 2018) If population forecasts continue on target, health care costs associated with long-term care could be astronomical for an already strapped health care system. ("Health Care Experts Hope For Long-term Reform", 2018)

An alternative, home care services in Ontario are available for seniors with complex medical conditions on a short and long-term basis. The goal of home care services is to help seniors continue living independently in their own homes for as long as they choose, and is reserved for seniors needing a higher level of care, for example those who are returning from a hospital stay or are experiencing significant illness. Services are administered by Local Health Integration Networks, and depending on level of assessed need, seniors are eligible for up to 35 hours of support. This may include personal care, occupational therapy, physiotherapy, social work, speech and language support, and nursing Care.

However, home care has been criticized for being unreliable or inadequate. High rates of staff turnover due to poor working conditions and low pay have resulted in lack of consistent and trusted relationships. Seniors have little control or choice over who they get as a personal care worker - whether they feel a sense of comfort and trust with them - or option as to when a worker comes and for how long. (UHN OpenLab, Aging Suit)

There is also a sense that home care policies are set too narrowly to fulfill the full breadth of needs that allow seniors to remain aging in place. Personal support workers are not allowed to help with many of 'the little things' that help seniors to live independently – for example throwing in a load of laundry, helping with grocery shopping, or heating up a meal:

"The shortfalls of homecare include staff turnover – which means seeing someone different at your door each time – and limitations on what home care workers can offer. As a Community Health Worker explains, 'If something isn't in the care plan, I can't do it, no matter how simple it is. I can't chat or socialize with clients at all, take out the garbage, make toast or a snack. Clients ask me to do little things, and they get frustrated when I can't do it – they are not in charge of the services.'" (Cohen, M. & Franko, J., pg. 10)

The Role of Informal Support

Another important consideration when it comes to aging in place is the amount of informal support that is required for people to live independently as we age. Although publicly available home care fills in many of the gaps, many seniors need to supplement their government-provided services with informal care, typically provided through a patchwork of support from adult children, friends or friendly neighbours. In a recent survey of 131,000 home care clients age 65 and older, only 2% were managing to get by without the support of an informal caregiver. (CIHI, 2010)

Caregivers fulfill a wide range of care needs, including meal preparation, medication management, shopping, dressing, bathing and toileting, and emotional support. On average, Canadian family caregivers provide seven hours of help for every two hours of professional care. (Donner, 2015)

However, trends in living and employment patterns suggest that traditional informal support networks might be under threat. Adult children are moving further away from home than previous generations. They are also having children later in life, and working more extended hours resulting in a situation where many adult children are being stretched to provide care for small children and elderly parents at the same time. Dubbed the 'sandwich generation,' this cohort has little room for taking mom or dad grocery shopping or helping out with a load of laundry.

Not unexpectedly, the reliance on informal caregivers has spawned a new category of health care concern – that of caregiver burnout. Caregiver burnout happens when a spouse or family member, who acts as a primary caregiver for a senior spouse or parent, experiences undue stress, burnout and health issues of his or her own.

"Extensive research demonstrates that prolonged and challenging family caregiving can induce a litany of adverse physical and mental health effects - i.e., weaker immune responses, chronic sleep disturbance, cognitive decline, etc. Such adverse effects can also threaten the quality of care provided to the care recipient." (Hughes, 2008)

Informal caregiving remains largely unrecognized and unaccounted for in the service design of home and community care. Nonetheless, it plays a pivotal role in keeping seniors safely at home for as long as they choose.

The Social Isolation Gap

Although old age is something that awaits everyone lucky enough to live a long life, for some the experience of aging in Ontario is typified by a sense of loneliness and isolation.

Social isolation is defined as a situation of *“few social contacts and few social roles, as well as an absence of mutually rewarding relationships with other people.”* (Keefe, et al., 2006) It is a complex phenomenon involving one's physical, social, emotional environment, and can operate at the individual, community or societal level. (Keefe) Social isolation is difficult to define, and measure precisely, although more and more attention is being paid due the health consequences that can come as a result.

A recent meta-analytic review suggests that social isolation exceeds obesity and physical inactivity as a risk factor for mortality. (Holt-Lunstad, 2010) The Public Health Agency of Canada reports that people with adequate social relationships are at a 50% lower risk of death than those with inadequate or insufficient social connections. (Public Health Agency of Canada, 2015)

Furthermore, a 2014 report by the National Seniors Council found that a lack of a supportive social network is linked to a 60% increase in the risk of dementia and cognitive decline, as well as increased risk of developing mental health issues, thus perpetuating the cycle of isolation. (National Seniors Council, 2014)

Although social isolation can occur at any age, it has been found that old age is a factor, due to the loss of daily contacts resulting from retirement or death of family members or friends. (Miedema, 2014)

Other risk factors that have been found to contribute to social isolation in older age include:

- Living alone
- Being age 80 or older

- Having compromised health status, including having multiple chronic health problems
 - Having no children or contact with family
 - Lacking access to transportation
 - Living with low income
 - Changing family structures, including younger people migrating for work and leaving seniors behind
 - Location of residence
- (National Seniors Council, 2014)

In 2005, the Ministers Responsible for Seniors in Canada endorsed the need for action on five key areas that directly impact seniors' health. Social connectedness was number one on the list. (Healthy Aging in Canada: A New Vision, A Vital Investment From Evidence to Action, 2006)

Housing as a Determinant of Health

Research conducted for this study found that many seniors feel that publicly-funded home care options tend to fall short in addressing the social determinants that allow seniors to remain vibrant: access to food, access to health care, homemaking, transportation, social connection, and especially housing. The seniors interviewed for this study called for a social determinants of health approach that addresses the upstream factors that keep seniors healthy and able to live independently, longer.

For these seniors, housing is a significant factor in that it is one of their largest, if not the largest, personal expense. Aside from affordability, housing and the physical design of the community define the nature and type of social interaction available to seniors who are less mobile. Housing therefore plays a significant role in understanding social isolation:

“Many seniors are mis-housed, ill-housed or even un-housed because they lack, or feel they lack, appropriate housing options specifically for them... Home is more than a roof over one's head or

financial investment. It affects the quality of a person's general well-being – one's confidence, relationships, and even one's health. It can provide a sense of security and comfort, or elicit feelings of frustration, loneliness, and fear." – Charles Durrett, Seniors Cohousing Handbook.

There is an opportunity to look towards emergent models of supportive living that are being developed at the grassroots level by end-users. Ones that take into account the ancillary supports that allow seniors to live happy, independent lives in the conditions that they choose.

The models described here may provide a blueprint for improved strategies to facilitate aging in place and reduce social isolation for seniors.

Project Overview

Aging Well is an exploratory research project aimed at uncovering grassroots models of seniors' supportive living that are emerging across Canada and the United States. The research takes a lead user approach to explore and describe new models of senior living and supportive care. It seeks to find emergent patterns amongst grassroots initiatives, and to provide a distillation of insights that these groups are employing in their quest to age well in community.

The findings from this research provide a baseline understanding of four models: Homesharing, Senior Cohousing, Naturally Occurring Retirement Communities with Social Service Program (NORC-SSP), and Virtual Villages. The project report includes information related to key elements of their design, including eligibility, funding and costs, governance, key partnerships and supportive services. The intention is not to develop a protocol for one all encompassing solution, but rather to offer inspiration and a set of guiding principles to help those interested in developing alternatives to currently available supportive living models.

As the health system faces growing demand on services that support aging in place, home and community care is emerging as an area ripe for innovation in service delivery. Given the intersectoral nature of aging in place – meaning it touches multiple areas of planning and infrastructure, including the health care system, housing, finance, municipal services, family systems – any new solutions need to be thought about from a holistic perspective.

As such, the assertion of this paper is that any 'innovation conversation' cannot happen without meaningful participation from seniors themselves. It acknowledges seniors as untapped resources to redefine what aging in community might look like. After all, who understands aging better than seniors themselves? In a sense, it is an attempt to listen deeply to the voices of seniors and to incorporate their input into future care planning.

The two key research questions that guided this research are:

- *What might we learn about 'aging in place' from user-generated models of seniors' supportive living?*
- *In what ways do these grassroots models address the issue of senior social isolation?*

The Lead User Approach

The story is the same across the board: seniors are looking at the currently available options for supported living and are asking themselves “are we really going to end up like this?” Seniors interviewed for this study expressed deep concern about not having enough support to manage on their own, or worse, ending up in an institution. They report that many among their cohort are merely avoiding thinking about it altogether. However, being forward-looking seniors, they are not accepting the status quo. They are actively looking for alternatives. And instead of waiting for the outside to provide solutions, they are simply building new models themselves.

These solutions are largely grassroots initiatives; developed locally by community, to meet the needs of local community. In some cases they are being designed entirely by seniors. As such, they may provide a window into what seniors who are hoping to age in place want, what they value, and what they feel they need to survive and thrive in life’s later years. These are real examples of lead user innovation.

The term ‘lead-user innovation’ was developed by Eric von Hippel in 1986 to describe an approach to research and development whereby companies can gain market advantage by incorporating product ideas that are generated directly by consumers. In his seminal paper *Lead Users: A Source of Novel Product Concepts*, he described two main characteristics of lead users:

- Users who face needs that will be general in a marketplace – but face them months or years before the bulk of that marketplace encounters them;
- User who are positioned to benefit significantly by obtaining a solution to their needs.

The notion that consumers can add value to the R&D process was, and still is, a disruptive idea. Dominant paradigms suggest that only experts or qualified researchers can develop new products

and services. In my experience working as a design researcher at UHN OpenLab, a health innovation lab in Toronto, it has been our experience that a reliance on qualified experts is especially true in the health care sector - a traditionally hierarchical, science-based environment where ideas are formed in a top-down manner. Experts are gathered; research is defined and commissioned. This process is slow, and not necessarily agile enough to deal with some of the intersectoral issues that affect health and wellbeing.

However, things are changing. As ‘Patient-Centered Care’ becomes the dominant framework for thinking about the design and delivery of care, new methods of patient engagement are coming along with it. For example, patient and family advisory councils (PFAC’s) are now the norm in Ontario-based hospitals. And with the recent passing of the ‘Patients First Act’ in 2016, each Local Health Integration Network (LHIN) is now required to establish at least one PFAC to inform its decision-making. (Ontario Ministry of Health and Long-Term Care, 2018)

Furthermore, co-creation is gaining ground as a popular modality for working with ‘patients as partners.’ (Freire, K., and D. Sangiorgi) However, in practice, both of these approaches remain largely in the realm of consultation, rather than true collaboration or co-creation. This may be due to a low tolerance for risk within the health care system, or beliefs about what credentials are needed before ideas are deemed valid. Von Hippel’s “user as innovator” approach may provide value in this context, as it takes the idea of ‘patients as partners’ and pushes out even further - patients are no longer just partners, they are creators. They are experts of their own experience, and makers of solutions. Lead user innovation as a source for R&D in the Ten clinics were randomly chosen, and 262 surgeons participated in the study. Twenty-two percent reported developing or successfully modifying, an item of medical equipment for their own use. Lüthje then studied the commercial value that these innovations had in the marketplace. The study reported

that 48 percent of the innovations developed by these user-innovators were either already, or soon to be, adopted by medical equipment manufacturers and sold commercially. (Lüthje)

Another compelling argument for supporting user-innovators is the cost. In 'How Communities Support Innovative Activities: An Exploration of Assistance and Sharing Among End-Users' researchers found that, without exception, monetary profit is not a fundamental motivator for developing new ideas. Instead fun, enjoyment, and the intrinsic motivation that comes from enjoying the task at hand are the main reasons for participation. (Franke and Shah 2003) They also found that user-innovators share their innovations freely within their communities as a way to ensure "reciprocity of information and support" and to help encourage further improvement by others. (Franke and Shah 2003 pg. 4-6) In a way, communities of lead user-innovators can be seen as mini-laboratories, providing low cost/no cost research and development into emerging marketplaces or gaps in current system offerings:

"Lead users are users whose present strong needs will become general in a marketplace months or years in the future. Since lead users are familiar with conditions, which lie in the future for most others, they can serve as a need-forecasting laboratory for marketing research. Moreover, since lead users often attempt to fill the need they experience, they can provide new product concept and design data as well." (von Hippel, 1986)

Prototypes of the future

In a sense lead user innovation can be read as 'prototypes of the future'. To quote science fiction novelist William Gibson, "the future is already here – it's just not very evenly distributed". (National Public Radio, 1999) Meaning, sometimes the solution to one group's problems may already be successfully solved by another, they've just have not heard about it yet. In the case of healthcare, this is a common problem – and not just in a global

context. It happens at the country, province or city level. Healthcare is notoriously slow when it comes to the amount of time it takes for new knowledge to be adopted into practice. Some estimates have it pegged as high as 17 years. (Morris, Z. S., Wooding, S., & Grant, J., 2011) For many seniors, this is simply not good enough, and they are not waiting.

Seniors over 65 years old account for 46% of public-sector health care dollars spent –more than any other demographic group. (CIHI; 2017) Sadly, instead of seeing them as able to provide useful insight into what is working, what is not working and how things might be improved, we often push them aside. Many people interviewed for this study report being treated as if their opinions are no longer sound, or that they are no longer able to make decisions for themselves. From a design perspective, this is a tremendous loss give that it is this exact cohort who are the ones that have the experience and wisdom from which we may benefit.

Von Hippel defined a four-step process for how to incorporate lead user innovation into research and development:

- Identify an important market or technical trend;
- Identify lead users who lead that trend in terms of (a) experience and (b) intensity of need;
- Analyze lead user need data;
- Project lead user data onto the general market of interest.

This paper uses von Hippel's lead user approach to look at the issue of aging in place and seniors' social isolation. It studies solutions being developed by communities who are facing these issues themselves, analyzes their approaches, and creates a set of design principles that the health system can use when developing supportive living services in communities that face, or may soon face, a similar demographic imperative.

Research Process



Part 1 – Environment Scan

The first phase of this project consisted of an environmental scan to understand the contextual landscape of aging in place and seniors' social isolation in Ontario. A literature review of peer-reviewed and grey literature was conducted to understand key challenges, as well as demographic changes, and social and values trends in contemporary aging.

Secondly, an environmental scan of grassroots senior supportive living models was undertaken using the lead user framework developed by Erik von Hippel (see page 8). It sought out working examples of grassroots seniors' supportive living programs operating in Canada and the United States. Data sources were found on the web by using key search terms including senior living, grassroots senior living, senior supportive living, senior care, elder care, home care, alternative retirement model, retirement homes, retirement living, retirement village, senior assisted living, nursing home.

The inclusion criteria at this phase included the initiative being a non-profit endeavor, and developed by community for the community, with a stronger emphasis on seniors-led examples. Since these models are still relatively nascent in Canada, the field of research included both Canada and the United States. This was undertaken so that active communities with longer histories of implementation could be studied. The United States was also chosen due to its geographic proximity and similar demographic imperative to Canada.

Examples were identified and analyzed to understand the core elements of their design: eligibility, funding and costs, governance, key partnerships and supportive services. These programs were then grouped according to similar features, and emergent models were identified. Four models were identified for further investigation: Homesharing, Cohousing, Naturally Occurring Retirement Communities with Social Service Program (NORC-SSP), and Virtual Villages.

Part 2 – Phone Interviews

To gain a deeper understanding of the models found during the environmental scan, semi-structured phone interviews were conducted with representatives from those grassroots initiatives. Twenty (20) hour-long interviews were completed. Three (3) sites did not respond, and three (3) sites declined participation in the research.

These phone interviews focused on fact finding about each initiative's history and current status, as well as core elements of the model's design. The interview guide (see Appendix A) consisted of thirty (30) questions, covering themes such as support services, decision-making, funding & costs, and enablers and barriers.

Part 3 – Ethnographic Site Visits

3.a Inclusion Criteria

Using findings from part 1 and 2 of this research, a set of inclusion criteria was developed to identify initiatives for site visits. Criteria were designed to reflect the goals of the project: to identify grassroots models of seniors' supportive living that embody a user-innovator approach as defined by Von Hippel, and address the issues of aging in place and seniors' social isolation:

- Not-for-profit
- Located in North America
- Lead user developed
- Addresses seniors' social determinants of health, including social connection, home maintenance, home-making, transportation, access to food, access to health care services, financial resources, and safety
- Have developed a specific protocol for health care supports
- Already implemented; not in a development phase

Additionally a mix of urban and rural initiatives was sought, as well as ones that ranged in terms of cost to participate.

3.b. Observations and Interviews

A total of four (4) sites was visited, one for each of the identified models in the environment scan: Women's Housing Initiative Manitoba (Homesharing), Harbourside Cohousing (Senior Cohousing), Co-op Village NORC (Naturally Occurring Retirement Communities with Social Service Program), and Verde Valley Caregivers Coalition (Virtual Villages).

These four specific sites were identified through web resources, including a Globe and Mail article about homesharing; the Village 2 Village Network a organization which maps Virtual Villages in North America; through the Canadian Senior Cohousing Society, an organization which seeks to promote senior cohousing in Canada; and through discussions with the New York State Office for Aging, which administers all NORC programming in New York State.

The researcher found contact information for these sites via their website or facebook page, and sent an email to introduce the project and set up a time for a phone interview. A follow up email was sent requesting an ethnographic site visit, which would include interviews with members and founders, as well as multimedia documentation.

The Researcher spent between two and four days at each site to take in the full sense of each community initiative. Ethnographic research consisted of:

a) Semi-structured interviews with between four and six members of each community including residents, founders, staff and volunteers (see Appendix B)

b) Ethnographic observations of daily life, including in two cases, staying in the caregiver suite of the grass-roots initiative being studied; observation of social and recreational groups including a debate class and bridge club;

c) Participation in community activities including home visits with a social worker, a ride-along to a cardiologist appointment and to a food bank, a neighbourhood walking tour, community yoga class, and several community dinners. Activities were chosen based on scheduling of interviews and what was happening during the time the researcher was on site.

d) Multimedia Documentation: qualitative data was captured using audio recording and photography. Audio recordings were done at the same time as the semi-structured interview, and consisted of the entire length of the one-hour interview. Photographic documentation with human subjects happened after the interview was complete and coincided with direct observation of interviewees in their homes or during their chosen community activities. The photography sessions lasted about one hour per subject. Environment and location photography was captured at a separate time, with the researcher visiting sites that were pointed out during the semi-structured interviews with participants. These sessions lasted from 3-8 hours and coincided with direct observation of the environment in which these initiatives emerged.

Part 4 – Analysis

Research materials, including field notes, photographs, and audio recordings were included in analysis. The goal was to understand key features and benefits of each program, as described by user-innovators themselves. Secondly, the research attempted to gain understanding of underlying needs or gaps that drove the initiative's development.

Semi-structured interviews were audio recorded using professional equipment for the purpose of analyzing user experience data, and transforming them into audio documentaries. Interviews included data about personal histories, values and beliefs, and key features that were driving participation. Analysis happened through the process of both capturing and editing the audio documentaries, as they put the researcher into deeper contact with the user's experience through repetitive encounter with words and stories.

Secondly Robert. E. Stake's notion of 'categorical aggregation' was used as a guiding framework for analysis. His inductive approach to case study research focuses on the interpretation of individual instances that the researcher finds significant, and though an "*aggregation of instances until something can be said about them as a class.*" (The Art of Case Study Research, Robert E. Stake, pg. 74) John W. Creswell reframed this approach in his book 'Qualitative Inquiry and Research Design: Choosing Among Five Approaches': "*In categorical aggregation the researcher seeks a collection of instances from the data, hoping that issue-relevant meanings will emerge.*" (Creswell, pg. 102)

Lastly, the KJ Method of affinity clustering was used to find emergent connections between grassroots initiatives, which underpin the user centered design principles articulated on page 72. (Scupin, 1997)

Limitations of the Study

An attempt to place an equity lens on site selection for the study was made, however the environment scan turned up initiatives that have largely been developed in hetero-normative, Caucasian populations. It is out of the scope of this paper to determine why this should be so, although some conclusions may be drawn around who in our society has traditionally been granted agency, power, and personal resources to donate time and money to building new paradigms of care. Lastly, as the search was limited to published materials and news items, the research was limited to the lens that media put on storytelling – which often shares a lack of diversity in its subjects.

In the future, models that have greater representation of ethno-cultural heritage, gender-identification, and economic means should be sought out for study. Additionally, greater diversity in rural, urban, suburban and inner suburban landscapes would be beneficial.

There are many models of senior's supportive living and retirement living options in Canada. Describing the various types and what they offer is out of scope for this study. The emphasis here is on looking at grassroots models being developed on the margins and in the gaps that exist in currently available options.

Lastly, the models and initiatives included in this study are situated across two countries and four provinces/states with vastly different health care systems. A description of each of those systems and what they offer in terms of assisted living for seniors is out of scope for this study. A good overview for Ontario can be found by looking at the Assisted Living Services for High Risk Seniors Policy report that was put out by the Ministry of Health and Long-term Care in January 2011.

"NORC-SSPs provide a unique opportunity for older adults and aging service providers to rewrite cultural perceptions of aging and promote images of aging and older adults that shatter norms of the old as frail, weak, and vulnerable and that create a new image of older adults as capable of controlling their own destinies given the proper resources."

- Fredda Vladeck,
A Good Place to Grow Old, 2004

Findings: Grassroots Models of Senior Living

After engaging in the environment scan using the lead user approach, and conducting phone interviews with representatives of various initiatives, four models of senior social living were selected for study. Example initiatives of each model was chosen for field research:

- Homesharing : *Women's Housing Initiative Manitoba in Winnipeg, Manitoba*
- Senior Cohousing: *Harbourside Cohousing in Sooke, British Columbia*
- Naturally Occurring Retirement Community with Social Service Program (NORC-SSP): *Co-op Village NORC in New York City, New York*
- Virtual Village: *Verde Valley Caregivers Coalition in Sedona, Arizona*

Fourteen days were spent at five sites across Canada and the United States. Twenty formal interviews were conducted, and there was engagement in observations, community activities and audio and photographic documentation.

The following section provides a general description of each senior social living model, including information about its benefits and drawbacks, which were distilled from a combination of primary and secondary research.

The general description is followed by a specific description of each study site. This section includes an overview of the initiative's core design elements, including the identified gaps and needs that drove its implementation.

Additionally, a narrative description of the site from the researcher's point of view is included. This 'A Day in the Life' section includes documentation from each site visit, including photographs and audio documentaries of user experiences. They are intended to deepen our understanding of the model and the value it brings to the lives of the seniors who are participating in them.

Lastly, for each senior social living initiative visited, there is a list of key ingredients, which outlines successful strategies for aging in place and reducing senior social isolation as articulated by research participants. These are synthesized from user experience interviews and observations.

MODEL 1: HOMESHARING

Homesharing is a shared living arrangement whereby two or more unrelated people live together in a single dwelling. Much like a traditional roommate(s) situation, residents share common areas, but have their own private bedrooms. However, unlike traditional roommates, there is a specific intention to provide support to co-residents and to help them age in place. Supports may include help with home maintenance, grocery shopping and meal prep, accompaniment to medical appointments, housekeeping, transportation and companionship.

Homesharing as a seniors' supportive living concept was originally established to benefit older adults who need extra help to remain living independently, but do not have the means to pay for private services. Currently, there are two main models of homesharing: the first consists of a peer-to-peer relationship that involves individuals closer in age moving in together and forging a partnership in aging. This typically involves a homeowner seeking out people to rent one or more of their extra bedrooms. A formal agreement is drawn up that outlines governance structure, expectations of mutual support, shared costs and responsibilities, and other household policies.

The second model is geared towards intergenerational support, and is typically made up of seniors and university students. The elder homeowner receives help with the chores they can no longer perform and receive a boost in income, while the younger homeseeker gains access to affordable accommodation in an area that might not have been otherwise available, as well as a sense of home life and security.

Homesharing pairings can happen organically, with interested parties finding one another through informal meet-up groups and online postings. Or it can happen through formal Homesharing services, which employ matchmaking services. Formal homesharing programs have a strong history in the United States, with over 350 programs, some operating for over 25 years. Currently, there are 4 official programs in Canada, with some providing intergenerational in addition to peer-to-peer matching services. However, it is important to note that there are likely numerous self-initiated homesharing arrangements that are not well documented.

BENEFITS

Affordability

Due to increased costs of living, many seniors in urban centers need help paying rent and/or property taxes and mortgage. This arrangement can be mutually beneficial through cost savings on rent and utility bills, or may act as a supplementary source of income. Homesharing also presupposes that roommates will share household duties such as cleaning, home repair, meals and groceries, and pet care, etc. In the case of intergenerational sharing, this may take the form of a bartered exchange for reduced rent. The intent is to ease the burden of maintaining a home as one ages.

Autonomy

The degree to which roommates support one another is negotiated locally and is not mandated by formal agencies providing matching services. The degree to which shared living or personal care is offered is entirely up to the participants themselves. Seniors remain in control of the type and intensity of support they receive with housemates acting as informal caregivers who offer support with daily living.

Built-in Network of Support

Equally significant is the emotional or social support offered by housemates. Homesharing helps reduce isolation, and provides a sense of increased security.

DRAWBACKS

Decreased Privacy

Sharing a home means having less privacy, as well as having to compromise and deal with each other's habits.

Compromise

In some cases, housemates' expectations with regards to mutual support may be more or less than desired. Additionally, seniors need to make concessions regarding personal belongings, and whose furniture, art, and household items are going to be used or displayed. This can be especially difficult for people who are attached to their belongings. Consensus decision-making may be difficult or undesirable for people who are used to living alone.

Uneven Power Dynamics

The Homeowner may have more actual or perceived power over household decisions due to the ownership/lease of the house or apartment resting with them.

Labour intensive to start

Homesharing programs that employ a matchmaking service need to do extensive background checks in order to find suitable matches and ensure safety. They may also experience an extended start-up phase if they do not start with a sufficiently large pool of home providers and seekers. For informal programs, it may be hard to find people willing to give this relatively new idea a try.

WHIM

WOMEN'S HOUSING INITIATIVE MANITOBA

The Women's Housing Initiative Manitoba is a grassroots homesharing initiative for older women who want to age in place with other older women. Their goal is to offer shared housing for women who are retired, or nearing retirement, and living on a low to moderate fixed income. More significantly, they want to help alleviate seniors' social isolation by creating an intentional community of women who care about and for one another, and who work together to prevent the need for institutional living.

WHIM is located in south-central Winnipeg close to the Assiniboine River. It is housed in a large three-story brick home, with 5 bedrooms, 3 bathrooms, 2 living rooms, and two guest rooms in the basement. It has the air of an old southern manor, replete with big trees in the yard and two white columns flanking the entrance. Currently there are four women who share the home, who span in age from 58 to 71. Three are retired; one is still working. Most are engaged in some form of volunteering or community work.

Costs are economical with rooms ranging in price from \$700-950, depending on the size, and includes bi-weekly housekeeping and all utilities. The women have a shared grocery purchasing system and each cooks one dinner for the household per week. The idea is to create a shared home and shared life, where seniors are engaged in a relationship with other senior housemates, but also have the space and privacy that one may desire.

For many older women living alone, loneliness and isolation are threats to one's health. WHIM maintains that women need to be in relationship with others in order to feel vital, and that making new connections, or maintaining old ones, is harder as we age. The easy connection and built-in support of the WHIM initiative is key to bridging that gap. Conversation is just down the stairs; there is the stability of mutual support.

As most of the women are currently on the younger side of elderhood, they do not have many needs in terms of health care supports at this time. However, the group has developed protocols for how they might support one another as they age – for example, how much personal care they are willing to give and receive from one another; what types of modifications they might need to make to the property to remain aging in place. Most of the support at this stage remains in the realm of social connection, companionship and emotional support.



fig. 5 / Bev Suck, 72, owner of the house where the Women's Housing Initiative of Manitoba (WHIM) was formed in 2015.

CORE ELEMENTS OF WHIM MODEL

Eligibility

WHIM is first and foremost an initiative for women – a way to address some of the equity issues that older women face. It is open to women over 50, as they believe that people don't really start to think about aging issues and how they will remain living independently until that point.

The process for applying follows this pattern 1) go for a tour; 2) fill out an application form and values questionnaire; 3) participate in a group interview. Identified qualities that are desirable for WHIM housemate's include flexibility, openness, and not being "too needy". Initially they held community meetings to discuss 'retirement options for women' to find potential housemates. Now that it is more established, they use social media and word of mouth to find new members.

Funding & Costs

Bev owns the home, and roommates share all monthly costs by a percentage that is based on the size of each personal room and its amenities. Prices range from \$700 to \$950 per month. This includes the cost of utilities, a housekeeper every 2 weeks, snow shovelling, as well as cable, water, taxes, heat, and landline telephone.

Each week, roommates put \$50 into a brown envelope for groceries. If someone goes shopping and pays from her own pocket, she would be reimbursed from the fund. There is an additional monthly fee of \$50 to build up a contingency fund for larger maintenance issues.

Supportive Services

As loneliness was a driving factor for most of the women to join WHIM, the social and emotional support they give to one another plays a significant role in maintaining health and wellbeing. However, they do also offer support in the realm of daily living: grocery shopping, housekeeping, home maintenance, bill payments, and gardening are shared responsibilities.

ties, thereby easing individual burden and the stress that may come with having to manage on one's own.

They share meals during the week, taking turns cooking for one another - which they say helps to strengthen social bonds, reduce isolation and improve nutrition. They have also built two guest rooms in the basement, which can serve as living space for in-home nursing support, or extended family caregiver stays if needed.

WHIM is currently working on a more formal health and wellness policy outlining the type of personal care they are willing to provide as old age sets in. Their goal is to help each other stay out of institutionalized care for as long as possible, recognizing that home and community services will be needed for more intimate care such as bathing or changing briefs. All members need to have a dedicated a power of attorney and living will or health directive in case of illness.

Governance

The women of WHIM use a 'one person, one vote' system to make decisions, although they acknowledge most issues are decided on informally by consensus. They hold formal monthly meetings to discuss household issues, paying particular attention to conflict resolution.

Key Partnerships

Initially, the group was informally connected with a now-defunct community meetup group called 'Retirement Options for Women'. This group was formed to find like-minded women who were interested in investigating alternative models for aging in place, in community, and was helpful in finding women who might be interested in joining up with WHIM.

A photograph of a residential street in winter. In the foreground, a person wearing a dark coat and hat walks across a snow-covered lawn. To the left is a white two-story house with a porch. To the right is a large, ornate red brick house with white columns and a balcony. Bare trees are scattered throughout the scene, and the sky is clear and blue.

A DAY IN THE LIFE

—

*A NARRATIVE OVERVIEW
INCLUDING QUOTES,
AUDIO DOCUMENTARIES,
AND PHOTOGRAPHS.*



fig. 6 / The exterior of WHIM.

Beverly Suek, 72, formed WHIM in 2014 after she found herself living alone after many years of rich family life. Like many older adults of her generation, she had been through the experience of putting her mother into long-term care, and did not like what she saw: an institutional environment with little personal connection and no ability to make your own decisions. So she decided to do something about it: she and a group of women formed a committee and started exploring retirement living alternatives for women.

Initially the group was interested in pooling their money together to buy a property and build a retirement community more in line with women's values. But they quickly realized that this was simply out of reach for many older women, who are 80 percent more likely than men to be impoverished at age 65 and older. (NIR p.1) Erring on the side of action, and as a next best plan, Bev decided to open up her family home to roommates.

LISTEN TO BEV'S STORY:
www.seniorsocialliving.com/bev

Katherine Lowery, 64, is one of four housemates. She had been living alone with her adult son, and was becoming isolated and increasingly reclusive. She spent most of her days watching TV. She loved her house, but it was becoming too large to manage. She knew she needed something else. When she heard about WHIM at one of the community meetings she loved the idea. That night she drove by the house, and immediately knew it was the right thing for her and signed up. She gave her son a few months to find a new place, and quickly sold her beloved house. Although she said it was hard to give up her home she worked so hard for, and hard to downsize from an entire house into one room, she says she has “come alive” living at WHIM.

LISTEN TO KATHERINE'S STORY:
www.seniorsocialliving.com/katherine

For Lynda Trono, 59, loneliness and isolation were also big factors in choosing to move into a homesharing environment. After her separation, she was renting a beautiful condo with a gorgeous view, but she was lonely. She hated coming home to an empty house. She says, “*she made great friends with the sky*”, but it was not how she wanted to live. She knew she wanted more connection and community. She wanted to be able to share her life with other people, and to continue to learn and grow as a human being:

“I am very comfortable here. I am doing things I would have never done on my own... We had a big party on Human Rights Day, we had people come and write letters for Amnesty International. When you're part of

a household and you invite all your friends, and everybody invites their friends, it's a real nice gathering... There's always stuff to do; it's good. Keeps me alive and learning new stuff.”

Lourdes Belik, 66, is WHIM's newest housemate. She echoed the desire to create social connection as motivation for moving into homesharing. She found that building social connection was becoming increasingly difficult as she aged, as most socializing is built around couples or children, or work, which she was no longer apart of. But for her, the bigger factor in deciding to move into a homesharing arrangement was affordability:

“I lived alone. I was spending much more on food. Sharing the cost of food, hydro, heat, is more affordable. I was ok, but I couldn't travel. I haven't seen my family in Brazil for 15 years. There is always something happening that I need to take care of, like my teeth. I think I am saving about \$500 a month living here. I used to go out and eat all the time, because I didn't feel like cooking for one. I don't have to go out now; there are meals.”

‘LIFE JUST HAPPENS’

Life at WHIM is active and engaged. People come and go according to their own schedules, coming together for weeknight meals that they each take turns cooking. Conversation is casual, but there is also awareness of what each other is going through, and more importantly, what she is striving for.

On the night I visited, Lynda, who is a community pastor with the United Church, was cooking dinner and listen to CBC radio. She had been interviewed that day about the homeless crisis in Winnipeg as the temperatures dropped to double digits. When she finally came on, her housemates gathered around and they listened as a group, and laughed.

Other women have come and gone, but according to the group, most shared the experience of isolation that comes after the loss of a spouse, when children have grown and moved away, and when your career ends. There is an ease of relationship here - no having to pick up the phone and call someone to connect. There is no appointment-making necessary. They just walk downstairs, and life is happening.

"I have been on my own a long time and it's not easy. It's hard. You feel lonely. And you have to really work at being busy; taking on things and being involved. You have to be a little more self-disciplined when you're alone. And here it just happens."

– Katherine

'KEEPING THE MIND ALIVE'

There was another common theme among the WHIM housemates: the desire to 'keep the mind alive' and to 'drive your own life'. They spoke about the loss of engagement that happens to older people in our society as they start being 'taking care of', instead of thought of as valuable members of society with something to contribute:

"One day you're the principal of a high school and the next day you have no value. And we do that to seniors...all people want to be useful. They want to have a reason for being here, and we take that away from them." – Bev

Life at WHIM was reported as being a catalyst for community involvement. The energy of the group was mentioned as a reason that some were engaged in things they never would have tried on their own - like volunteering at a women's shelter once a week. However, it also seems that the very act of managing a shared home, and a shared life, gave them a sense of purpose and meaning.

"We are in control over the environment here - what we buy, what we eat, what we cook, the cleaning, everything. In a living assistance where you pay to live, I don't think you decided. Here we have meetings. We decided what are priorities and what needs to be done... Older people are usually infantilized, especially women." – Lourdes

Bev Suek owns the home, but she doesn't want to be the boss. It is important for her and the group that it is a truly shared household, with shared tasks and shared decision-making. They have been looking into other structures in order to facilitate this, and have been looking into turning the rental structure into a co-op. However, the buy-in rate is too high for many women to afford so for now it remains as is.



fig. 7 / Katherine in her room.



fig. 8 / Bev in the living room at WHIM

According to WHIM, in order to make an intentional community work, structure is imperative. There are monthly meetings where they discuss household matters, and have protocols for voting and conflict resolution: if you have a problem with a housemate, you address it with them directly and try to work it out. If you cannot work it out, then you bring it to the group. Additionally, each woman signs a contract that states if it just doesn't work out, then they have to leave. When I asked them about it they all seemed to understand that the needs of one person cannot put undue burden on the rest of the group, and that they have to have a degree of flexibility and openness to 'other people's way of doing things' in order to live here.

I asked about the challenges of transitioning from living on one's own, and making all of your own decisions, to compromising with a group of (at first) strangers. But for them the alternative is much worse. From their vantage point, the WHIM model will allow them to maintain the greatest amount of control over their own destinies, even as their health declines or they find themselves needing support with activities of daily living.

HEALTH SUPPORTS

None of the women are currently at the point where they have health issues that require outside services. But they are not 'sticking their heads in the sand' about it either. They have been working on a health care protocol for the house that details how much they are willing to give and receive from one an-

other, and are actively negotiating their boundaries with regards to personal care. So far activities such as cooking, cleaning, escorts to the doctors, transportation, and helping with medication management are all in scope; helping to change diapers is not. There are two guest rooms in the basement for when family visits, or if they eventually need more intense support.

The main idea is that WHIM will offer the kind of continuous support needed to stay out of institutional living, and will utilize home care services on a piecemeal basis. The expectation is not that WHIM will perform extensive care, but if any member does not feel able to cope or can't help out with household maintenance, there is no expectation for them to do so. At that point the other three roommates will need to decide if they are able to cover the work and carry on. If it doesn't work, then the person may need to find another place to live.

The women are putting this all into their contract so that expectations are clear and spoken. They say open communication is key to making it work – that this model can even help with having those difficult discussions around end of life that many families find challenging. Katherine calls herself 'a lifer' and is hoping to be able to die here, to have hospice come in when the time comes. *"It's nice to be around people that you love in the last days of your life".*

They believe they can provide the support that is needed – the emotional, social and intellectual connection to keep them vibrant – in combination with family support and government home care assistance will be enough to keep them there looking after one another until the end.

According to Bev, WHIM provides a level of continuous support that living alone with the help of public home care services is not able to provide:

“We treat the person like they’re not a person...home care is just a 15 minute run in and change a diaper, and then right back out again...it’s not an ongoing compassionate care...it’s like pieces and they don’t all fit together. There’s no continuity, and so it’s just not enough.”

“I find it really hard to describe the difference between... having a friend you go to a movie with once in a while [and homesharing]...It’s nice but you still go home alone.

You still have dinner alone...maybe a peanut butter sandwich or frozen lasagna or something... you don’t have that continual sort of support system... There’s a difference in terms of intimacy... I don’t know how to describe it - it’s friendship but it’s beyond friendship.” - Bev

They believe that senior-run programs such as their model of homesharing can work alongside government services to allow older women to remain aging in place for as long as they wish.

They know it is not a perfect system, and that they will have to keep revisiting this topic as they go on – but one thing is clear; they see this as trailblazing the way for other women to figure out how to stay vibrant and active in community, and to stay living in the community. All agreed that long-term care is the option of last resort, and very much see this as an antidote.

IDENTIFIED NEEDS AND GAPS FILLED BY THIS MODEL

- Social isolation
- Difficulty maintaining a home on one’s own
- Desire to maintain agency over one’s own life



fig. 9 / Lynda cooking a communal dinner.



fig. 10 / Lynda in the shared kitchen.

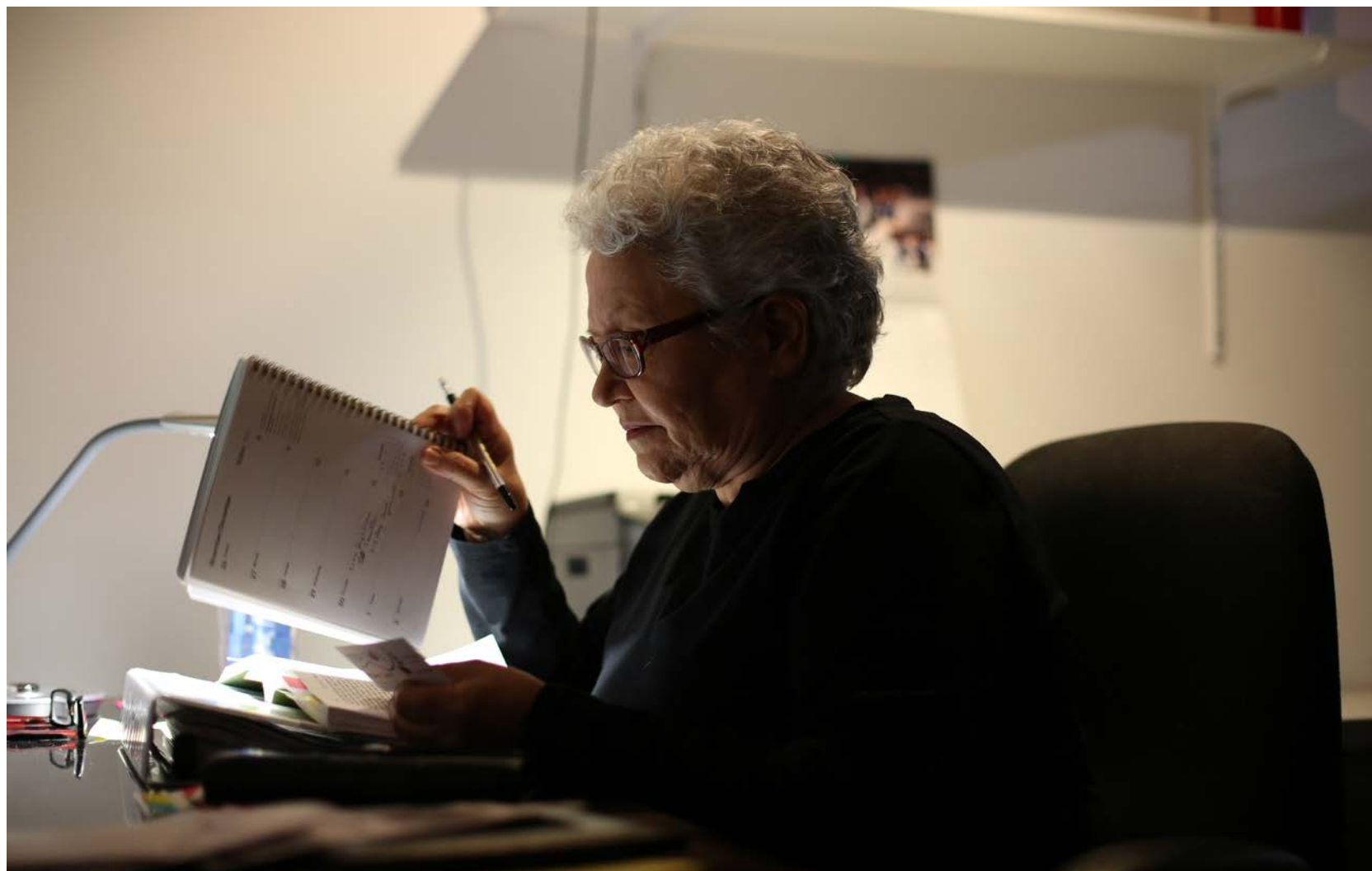


fig. 11 / Lourdes studying for exams in her office. She has recently gone back to university.



fig. 12 / Lourdes, 66, the newest member of WHIM, sharing a laugh with Bev, 72, the founder.

INGREDIENTS TO SUCCESS AT WHIM

1. Continuous Community Care

Outside of long-term care or the hospital, continuous support is not offered to Ontarians through the health care system. This level of support falls into the jurisdiction of our informal care networks. If adult children are busy or live far away, and a spouse has passed on, neighbours and friends may take on this role. By co-locating with friends or roommates who make a commitment to support one another – emotional, intellectually and physically – the time one can remain aging in place is extended.

2. Self-Determination

It is important for seniors at WHIM to continue being active participants in the community. Control over their environment and the decisions they make are a key. Making active choices and providing support themselves is providing them with a deep sense of mattering, purpose and personal value – which they say are keys to aging well.

3. Intellectual stimulation

Intellectual stimulation is critical to maintaining vitality. They do not perceive retirement homes or long-term care as places that stimulate intellectual or political curiosities, which keep 'the mind alive'.

OBSTACLES TO IMPLEMENTATION

Difficult to get insurance

Insurance companies are unfamiliar with community living models and have classified WHIM as a boarding house, which carries higher premiums due to an increased risk of theft. Insurance may be cheaper if they become a co-op.

Difficulty with municipal zoning

In some provinces, municipalities may define “family” in a way that prevents the establishment of a shared housing agreement. Building associations and landlords may not allow guest stays and rentals. In Winnipeg, boarding houses need to apply for a special zoning variance in order to be in residential neighbourhoods. This may be difficult to get due to stigma associated with homelessness, addiction and mental health populations more typically found in boarding houses.

Difficult to get people to give it a try

WHIM has had difficulty finding new roommates due to homesharing being a new idea and a foreign model of aging in place. Finding people to move in can also be challenging due to the need for downsizing. Lastly finding people who are the right fit can be challenging in such an intimate arrangement.

MODEL 2: SENIOR COHOUSING

Cohousing is a form of intentional living whereby a group of individual homeowners decides to enter into a formal agreement to buy land and build a mutually supportive living community. Typically, residents invest capital upfront and work collaboratively on designing all aspects of the community from infrastructure, governance, social mandate and co-care protocols. At its heart, cohousing is an attempt at recreating an “old-fashioned neighborhood where neighbors look after neighbours, and ‘community is a way of life’ (Durrett, 2009). Key features of this model are its shared ownership structure and commitment to mutual support.

While cohousing communities may vary, they always share 6 components (Durrett, 2009):

- Participatory decision-making process
- Deliberate neighbourhood design
- Extensive common facilities
- Complete resident management
- Non-hierarchical structure
- Separate income sources

Cohousing can be intergenerational, gender-specific, or seniors-only, among other configurations. Senior cohousing is generally made up of older adults who are pro-actively looking for ways to age in place, and are unsatisfied with currently available options. Ages range from people in their early 50s, to elders who are in their 90s. None in Canada so far are age-restricted but ages range.

A typical senior cohousing arrangement is made up of approximately 20-30 individually owned housing units, oriented around central common areas and a common house for socialization. These common areas supplement private spaces and are intended for daily living. Similar to condominiums, the costs for common amenities, landscaping and maintenance of the property are shared amongst the group. However, unlike condos, there is a social mandate to participate in communal living and to deliver mutual support when it is possible. Interdependencies are encouraged through multiple pathways, including the physical design of the space, governance structure, and social mandate of the community.

Senior cohousing has already spawned another important social innovation: that of community co-caring. Neighbours provide mutual support and act as an extended family, helping residents remain living independently for as long as they choose. As stated in the Canadian Senior Cohousing Society's Manual:

"People can support each other through such simple activities as doing errands, driving, cooking, or going for a walk with a neighbour. As their connection with each other deepens over time and through shared experiences, they may find themselves doing things for each other that they would not have dreamed of when they moved in." (Innovations in Seniors Housing, p.11)

Although multigenerational cohousing is the norm, there is a place for senior cohousing, especially in the context of co-care. According to Margaret Critchlow, one of the founders of Harbourside Cohousing, seniors in traditional cohousing found that they wanted to have quieter meals, but they also wanted people around in the daytime for company: *"The thing with multigenerational cohousing is that the adults are out at work, and the kids go to school, so nobody is at home."*

*IDENTIFIED NEEDS AND GAPS
FILLED BY THIS MODEL*

- Sense of community
- Desire to maintain agency over one's own life
- 'Precarious support'; insecure, uneven or unreliable care in the home

BENEFITS

Built in Network of Mutual Support

Social connection may be lost after divorce or death of a spouse. Making new connections increases in difficulty with age. Cohousing provides a built-in network of support and creates a cultural of reaching out to both ask for and receive support. Senior cohousing addresses many of the traditional barriers that prevent seniors from staying in community: adaptive/inclusive design for age-related mobility challenges, assistance with daily living: meals, chores, groceries, and light housekeeping.

Self-determination

Cohousing is community-led, as opposed to other types of planned seniors' residences that tend to be designed by business owners for a profit. This model puts the holistic health and wellbeing of senior residents first, with details about how to meet those needs worked out in an organic and collaborative fashion. This lends itself to a high degree of personal choice and autonomy.

Shared Costs & Responsibilities

Residents share expenses associated with running the community, including costs of common facilities (e.g. laundry room and community garden) and shared amenities (e.g. internet, hydro etc.) and paid services (e.g. maintenance, repairs etc.), as well as shared services (e.g. meals and transportation). This can save costs, promote eco-friendly and green living, and in turn improve sustainability of the community. However, residents maintain separate sources of income and maintain sole ownership over their private dwelling.

DRAWBACKS

High Capital Costs

Senior cohousing is a high cost endeavour. Residents need money to invest in the purchase. Most people sell their homes and downsize into one of these units. Some cohousing communities reserve a few rental units to help with the issue of equity and accessibility. There are some examples of retrofitting existing structures and implementing the mission, vision and values of cohousing, which may be less cost intensive.

Downsizing hard for people

Private spaces are small and usually require significant downsizing if a new member is coming from a single family home.

Emotionally intensive

This type of arrangement requires a large amount of trust and communication, with the ability to speak openly and honestly about one's needs. Requires strong interpersonal and conflict resolution skills.

Slow

New cohousing communities may take more time, money and energy to plan and develop than initially estimated. Members interested in forming a community may have to wait years before construction begins.

HARBOURSIDE COHOUSING

SOOKE, BRITISH COLUMBIA

Harbourside Cohousing is one of Canada's first senior cohousing initiatives. It is located on a large property that faces Sooke Harbour, on Vancouver Island in British Columbia. The complex consists of a number of duplexes and fourplexes, and a larger, condo-style building that is referred to as the 'apartment house'. There are 31 units that are filled by single people and married couples; renters and owners. In total there are 45 people who are part of the Harbourside community, ranging in age from 60 to 88 years old.

They call themselves an intentional community who came together organically around the idea of buying land and building a supportive living community that they themselves would run. Members are mainly retired professionals who have moved to Sooke to take advantage of the milder winters and beautiful landscapes. Over a period of five years the group worked collaboratively to flesh out the details of their community. This included governance protocols, community codes, financing and legal arrangements, and building designs.

They also began the initial groundwork for what would become their co-care agreement: a promise to provide a supportive and stimulating environment where every member can age in place if they choose. This aspect of Harbourside is what sets it apart from other cohousing initiatives. The big idea is that seniors who live in close proximity, and who share space, responsibilities and sense of community, can work together to reduce the harmful affects of social isolation and address the issues that enable seniors to age in place.

To this end, public space on the property is maximized while private spaces are more compact. There is a common house that has a communal large kitchen, two guest suites, an art room, an exercise room, and a nursing suite for when members may require more extensive care. The community meeting point is the common house. Neighbours meet here for weekly brunches, Sunday morning coffee, and group yoga classes.

Harbourside has incorporated universal design elements and adaptive features into the buildings to help keep seniors out of institutions for as long as possible. For example, extra wide doorways and ceiling tracks are installed for potential future installment of a lift to help get from bed to bath in units that opted for them.



fig. 13 / Harbourside Cohousing is located in the small town of Sooke, on Vancouver Island in British Columbia

The group moved in to Harbourside in January 2016, and has continued working on the details of their cohousing project ever since. Members take part on 'teams', which are responsible for various aspects of the community, from landscaping, finance and legal, community development and composting, etc. They also hired a professional project manager and an architect to get the project up and running, however they themselves remained the final decision-makers. Harbourside considers this a key element to the success of their implementation.

When original owners bought in, the price per square foot was around 400 dollars. In the two years since moving in, their equity has raised significantly as more people are moving to the island to escape the astronomical costs of living in Vancouver. In addition to initial capital to buy in, owners must also pay monthly fees. These are currently set at a standard \$350 per unit per month, which covers heat, maintenance and repair, and garbage removal.

However, there is some concern about sustainability of their current model and the potential need to raise fees as the community ages. Currently fees are set low, since the community is able to do much of the maintenance and landscaping work themselves. For some, an increase might mean that costs become too high to remain. For others, this poses questions about sustainability of the community and the need to have younger bodies around "to do the heavier lifting".

CORE ELEMENTS OF HARBOURSIDE MODEL

Eligibility

In the planning phase, the group was self-selecting – a coalition of the willing. Potential equity members had to take a course about cohousing, attend an information meeting, and meet with an assigned buddy to become familiar with all the decisions that had been made up until that point, including legal agreements.

Now that the group is up and running, there is no official eligibility criteria for moving in other than having the capital to purchase a unit. That said, existing members make every effort to ensure that potential buyers are familiar with cohousing and understand that they are buying into a community, not just a condo. Current members may encourage or discourage people from buying according to whether they believe the potential member will be a good fit.

Funding & Costs

Harbourside received initial support through a \$20,000 no-interest loan from Canadian Mortgage and Housing Corporation (CMHC) for a feasibility study.

The rest of the funds to develop the project came from the grassroots membership. The initial contribution was \$20,000 as a non-interest bearing, required shareholder loan. Members topped up their required shareholder loan to 10% of the price of their unit at construction start. Vancity Community Investment Bank provided construction financing.

Ownership is incorporated under a strata council or condo corporation title. Like any other condo setting, owners are free to sell their units whenever they want, and as of yet, they have not placed any restrictions on who they can sell to (see eligibility above). Legally, under the BC Strata Act, owners of any units including cohousing cannot impose such restrictions. Harbourside has some rental units, as well as one condo that they keep at 20% below market rate, which is subsidized by the other members.

Monthly strata (condo) fees are \$350 per month, per unit, which covers shared utilities, a contingency fund for major replacement costs, and part-time maintenance support.

Supportive Services

Harbourside has developed a model of 'co-care' in which members agree to support one another through old age and illness whenever possible, and wherever comfortable. What this exactly looks like is still under development, and will largely depend on what individual members decide they are willing to give, and willing to receive in the form of personal care.

The idea is to disperse caregiving duties amongst the community, and to help each other with such things as care coordination; advocacy; transportation to medical appointments; accessibility retrofits; or organizing benefits. Some members have started smaller couple to couple support groups to check in with one another on a regular basis. Additionally, the group has built a self-contained caregiver suite that is available if someone needs help for an extended period of time, or potentially, for the community to pay for a professional caregiver to come and support the community.

Other forms of support focus on increased social connection through community events, including weekly brunches and coffee mornings, a movie and discussion series; as well as group exercise and health promotion including a weekly yoga class held in the common house. They have also recently started a community freezer to support people who are not prepared to cook for themselves.

Governance

Harbourside is self-initiated and self-managed. The community holds monthly meetings and employs a consensus decision-making process. Members work through problems and proposals until there is general agreement. The process is time consuming and can be frustrating. However, it is viewed as an important step in creating harmony for the group and satisfaction for individual members who intend to live together for years to come.

New initiatives are member-led and member-developed, with the general rule being “if you want to do it and can get some people interested, then go for it.” Residents participate in small working groups or ‘teams’ to develop new proposals for the community. Once a plan is laid out, it is displayed on the community board for review and suggestions, before it is discussed at the community meeting.

Key Partnerships

The group has no significant partnerships now that it is up and running. However during initial development, they partnered with:

- Professional services to support initial construction and development: project management, engineer and architect
- Vancity Community Investment Bank
- Canadian Mortgage and Housing Corporation (CMHC)



A DAY IN THE LIFE

—
*A NARRATIVE OVERVIEW
INCLUDING QUOTES,
AUDIO DOCUMENTARIES,
AND PHOTOGRAPHS.*



fig. 14 / The exterior of HARBOURSIDE.

Harbourside Cohousing is beautiful. It is located on a two-acre parcel of land in the small town of Sooke on Vancouver Island, and boasts restorative views of the ocean from each of its 31 units. Many members could not afford such a prime piece of real estate on their own, but as a group, they were able to pool their money and buy it together. They are lucky, and they know it. But it's not just the land they feel lucky about – it's the community they've built, and continue to build, on the premise of mutual support and 'intentional neighborliness' - which they hope will prevent them from eventually having to move into institutional care.

The impetus for the initiative came from a group of friends: Margaret Critchlow, a retired anthropology professor, Gail Moore, an osteopath, and Andrew Moore, a consultant with a background in co-operatives who were in their late 60s at the time. Each had been contemplating options for aging in their own right, but together became seriously interested when they began investigating the cohousing movement championed by the architect Charles Durrett. All three went to a course he offers in California, and returned home inspired to start a senior cohousing project in Canada: Harbourside Cohousing.

MEANING & MATTERING

On the weekend I visited Harbourside, I had the opportunity to interact with many of the members, as well as interview 5 of them in a formal capacity. All but one had moved to Sooke from elsewhere in Canada, and all had some piece of the cohousing puzzle that they were bringing: one couple had started a life long learning program in Calgary and brought with them the expertise and how to start one up in Sooke (which they have); one was a primary care physician with experience caring for the health needs of seniors and interacting with the health care system in BC; another had taught a university course in space and place and had research experience in various models of collaborative living; and yet another had expertise in social planning and community development.

The group who volunteered to be interviewed were self selecting, although I came to realize that the cohousing group

itself was likely self-selecting, bringing with them a variety of skills and experiences that they were now putting to work in their community. David Hannis, the social planner, explained the parallels between cohousing and the tenants of community development in further detail:

“The philosophy of community development is people having control over their own lives. Celebrating the strengths that people have - given place for those strengths to be nurtured and celebrated and used. One of the things I see here is that there is space for people to use their talents...everyone needs a sense of place.”

For Bob and Arlene Stamp, 80, who have been married for 57 years, having a sense of community was the driving factor in moving into Harbourside. Not only to combat social isolation, but in recognition of the need to have a community of supports to call on as you age.

[LISTEN TO BOB & ARLENE'S STORY:
www.seniorsocialliving.com/bob-arlene](http://www.seniorsocialliving.com/bob-arlene)

After downsizing from a single-family home into a 1400 square foot condo in Calgary, they realized that simply moving into a more accessible space was not going to be enough to support them through older age. They had more neighbours around, but they didn't actually know any of them. And while they had good friends to go out with, their children had moved far away, and

the only real intimacy they had was with one another. The social isolation they sensed coming down the road was only more pronounced against the backdrop of harsh Calgary winters and decreased mobility. They quickly realized they had a “situation they needed to get out of”.

One of the reported benefits of the Harbourside model is the sense of meaning and purpose it provides for residents. Many noted the perceived loss of value that can occur after retirement as being a significant contributor to social isolation and loss of vitality in older adults. And they did not want to see this happen to them.

For Margaret Critchlow, having a cohousing project like Harbourside, to design and build, to work on, together, and to pour her energy and skills into, seemed to be providing a deep sense of purpose and meaning. There is a sense that your work matters, and that it is appreciated.

LISTEN TO MARGARET'S STORY:
www.seniorsocialliving.com/margaret

SELF-DETERMINATION

There are many ways to participate at Harbourside, from doing landscaping work, to putting out a community newsletter, to sharing a meal, to chairing the community meetings. However, participation is not tracked and no one is obligated to do anything. It is all voluntary. The group seems to work because members seem to share a vision for healthy aging that involves intentional commu-

nity building and mutual support. However, there seemed to be a fierce determination to balance the needs of the community as a whole, with the needs of individuals. One of the group's core beliefs is that all decisions need to be made by consensus. This, of course, takes time. And since cohousing requires a large amount of personal investment, finding people to commit with a down payment was difficult, as was making communal decisions about building specifications, community protocols, and legal and financial arrangements.

Beyond the initial building, governance is still done by the group-at-large, with members participating in a consensus decision-making process that is laborious, and at times, frustrating. They hold monthly community meetings, where issues and ideas are discussed and decided on communally. However, despite the emotional labour required to do consensus based decision making, they still believe it is the right approach for an intentional community hoping to build the bonds required to support one another through old age and poor health:

“This a community of people that wants to continue to live together happily. So we use consensus-based decision making instead of making decisions by majority vote, where you could have 49 percent of the people against a resolution and then it would still go forward...this is not a good basis on which to build a community inside a long-term community, especially a closely knit family-like community.” – Arlene Stamp



fig. 15 / Residents pool their money to bring in a private yoga instructor once a week.



fig. 16 / Warren doing this dishes after Sunday community brunch in the common house.

The desire to meet the needs of each member of the community is reflective both of their desire to build a compassionate community, but also a steadfast desire to retain agency and choice as they age. For Bob Stamp retaining control over where he lives and what decisions are made about where he lives is seen as nothing less than an acknowledgment of his “*viability as a human being*”, a lack of which he believes contributes to decline in seniors. According to Bob, we so often take agency away from seniors and start to treat them as though their opinions no longer matter. Cohousing is exercising the exact opposite of that, and in the process, providing Arlene and him with renewed sense of vitality.

CO-CARE

The tendency to think ahead and plan for the future is another defining feature of Harbourside. Many note the tendency that most of us have to avoid planning for a future when we will need outside support. This sense of ‘denial’ is something that Harbourside Cohousing is actively trying to combat by living in community and building strong networks of support before it is too late:

“Over the years I’ve watched a lot of people go along thinking that tomorrow will be much like today. And then something catastrophic happens and the world turns upside down, and they didn’t have any plan b... most people don’t have a plan B.” – Dr. Ellen Anderson

As a whole, the group is fairly young, and do not have many serious health care issues that need addressing now. However, much like the WHIM group in Win-

nipeg, they have started building out a ‘co-care’ protocol, which will set out some guidelines or principles about how the community intends to care for each other’s health. Dr. Anderson leads the group, and believes that co-care can help with the gap that exists between informal support from family or friends and publicly available support services, which is where a lot of seniors fall through the cracks.

“So let’s say you’re living in your own home, and you get bad arthritis. And then you lose your driver’s license and it’s hard to shop. Your hands hurt, so chopping vegetables is hard. And you can’t clean your eavestrough and you’re living on a limited budget. All your money is tied up in your house, which you want to leave to your kids, and you can’t afford to hire a housekeeper... or any help.”

“If you are referred by your family doctor for home care services... they’ll put somebody in your home... but you don’t get to choose who the person is, you don’t get to choose how often or what days they come, or what time.... It’s a rotating number of strangers, who you might develop a bond with over time, but you might not either. They will do some things for you, but they don’t cook meals. They don’t take you shopping...they don’t sweep your sidewalk or shovel the snow, or do any of those kinds of things. So that’s where the hole is.”

– Dr. Ellen Anderson

Harboursiders believe cohousing can fill in those gaps. Among other health supports, some early ideas for ‘co-care’

include help with care navigation, and advocating on behalf of members; providing a liaison between people and their families; building a co-care suite for family to provide palliative care or extra support when returning from a hospital stay; nutrition and exercise support; a co-care fund to help pay for private care services before public supports kick-in, and community events to prevent social isolation.

In many ways their co-care model is already showing signs that it works. Recently a member was diagnosed with Parkinson's Disease. He was not well and it was getting worse, so his wife put out an email to the group asking for help. She asked if anyone was willing to provide support for her husband on Monday nights, as she had singing lessons and really wanted to go. Being a jazz singer, she said these classes help "keep her sane" in her role as a full time family caregiver. The community responded by bringing lunch over on a daily basis, stopping by for 20-minute chats, and taking him out for walks. They recently got an email saying he was so much better.

The value of relationships to maintain good health as we age is a key principle that emerged at Harbourside. To feel heard and cared about; to have the opportunity to participate meaningfully; and to facilitate support for your neighbours, which one day you may need yourself.

For David Hannis, the social planner, aging well also involves redefining the image we have of aging in our society – from one that places value on 'the rugged

individual who takes care of themselves', to one that encourages people to ask for help:

"You have to respect people's privacy, but at the same time you need to know a little more about your neighbours...You don't want to be intrusive, but you need to signal that you care and reach out. And that to me is the critical element of aging in place: being able to ask for help when you need it. And also being there to give help if you think someone else needs that help; and giving that help on the other person's terms, not what you think they need, but what they need. What do they themselves see?"

For Dr. Anderson, aging well in place requires moving from a deficit image of seniors, to one that acknowledges the possibility of their contributions and value.

"If we view aging as a progressive decline in a series of losses then we can't see the possibilities ahead of us. But if we view aging as an opportunity to actually recreate different lives for ourselves and to lead our lives in different ways and to provide more support and connection in our communities then we get a lot of opportunities to do this really differently that aren't necessarily going to cost more."



fig. 17 / David Hannis is a retired social planner from Edmonton, who has joined Harbourside.



fig. 18 / Each condo unit has a view of Sooke, Harbour.

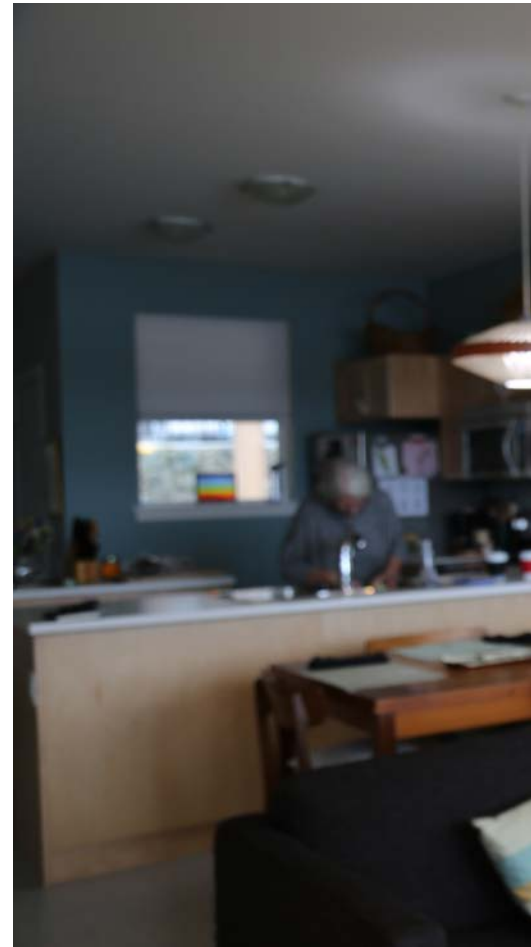


fig. 19 / Margaret Critchlow, 70, is one of the original founders of Harbourside Cohousing.



fig. 20 / Bob Stamp



fig. 21 / Arelene Stamp

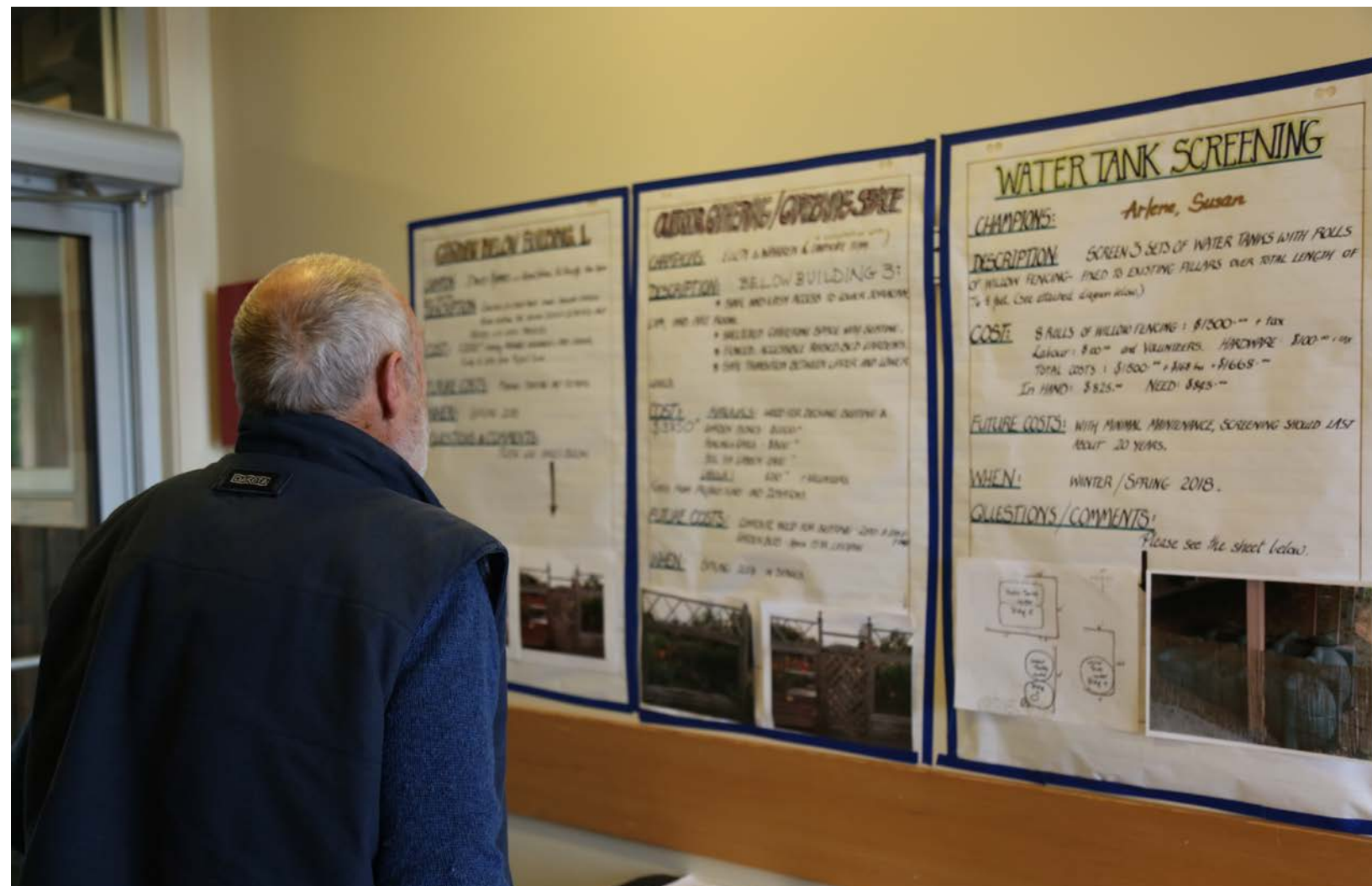


fig. 22 / Residents join 'teams' that take care of community planning and maintenance. All decisions are made by consensus.



fig. 23 / Members take part in clearing the beach. Participation is voluntary and not tracked, but instead based on willingness.

INGREDIENTS TO SUCCESS AT HARBOURSIDE COHOUSING

1. Focus on Relationship Building and Community Care

There is a perceived link between having strong relationships and healthy aging in place. This is largely due to the informal support that such relationships offer older adults who are in need of care. By creating a mechanism for the community to support one another, it lessens the load on any one individual, and provides more opportunities to get social, emotional and physical health needs met.

2. Self-determination

Cohousing as a structure for seniors supportive living is founded on the principles of active choice and participatory decision-making. This gives agency to seniors to imagine and build the kind of support environment they themselves desire. They decide what they want instead of it being imposed on them.

3. Providing Meaning and Purpose

Creating meaning through doing things, together, was a big theme. Being seen as a valued member of the community, and in the process, finding new ways to participate promotes flourishing as opposed to languishing at home alone. In order to prevent decline and stay out of institutions, seniors need to have meaning and purpose. Volunteerism is an important part of that.

OBSTACLES TO IMPLEMENTATION

Capital costs

Cohousing is still a relatively high cost endeavor. People have to be able to afford to purchase into the community. Although the homes are built at cost, with no developer's profit, members need to jointly pay for common amenity space, and often want extensive environmental features, energy efficiency, and aesthetic features that can result in the cohousing units costing the same as regular condo buildings. Low interest mortgages or no interest loans would likely help cohousing groups get going.

Difficulties forming a cohesive group

Group dynamics are key to successful cohousing. Groups may fail to move beyond the "potluck stage" if they don't develop the trust needed to invest their money together.

Project Management

Good project management is crucial to implementation. Groups that hire professional project managers report having greater success. Ground rules, clear processes and agreements also support projects to move forward.

MODEL 3: NATURALLY OCCURRING RETIREMENT COMMUNITY WITH SOCIAL SERVICE PROGRAM (NORC-SSP)

The term Naturally Occurring Retirement Community (NORC) was coined in the United States in the early 1980s to describe a geographic area that has naturally developed a high concentration of older residents. This phenomenon is due to seniors remaining in their own homes as they age, or because they have congregated to an area after retirement or downsizing.

NORCs exist in two main configurations: 'Vertical NORCS' that have developed in high-rise apartment buildings or co-ops; and 'Horizontal NORCS' or 'Neighbourhood NORCS' that encompass several low rise buildings or single-family homes. Typically a catchment is designated a NORC if it contains over 40-60% seniors, aged 60 years and above.

The NORC-Supportive Service Program (NORC-SSP) model was developed to wrap around these groups of seniors, and to help them remain living independently for as long as possible. In New York City, where the NORC-SSP model was developed, it was an early example of what a place-based model of senior's care might look like, which combines care delivery with community building efforts. (Vladeck and Altman, p.1)

The main idea of the NORC-SSP model is that by working with natural congregations of seniors, efficiencies in health and social service delivery can be achieved while remaining in alignment with seniors' goals: to stay living in their own homes. While the model does provide some direct health care services, it is largely a preventative model that acknowledges the need to provide support before seniors' health starts to decline and more intensive home care or acute care is required. It is also an acknowledgement that existing social networks play a key role in protecting the health and independence of seniors as they age.

Supportive services are offered in the building or immediate community, and attempt to address the social determinants that are not typically managed through government programs: social connection, system navigation, help accessing benefits and entitlements, and exercise, among others. NORC-SSPs that are government funded tend to support low to moderate income seniors. Core services for each program are unique and reflect the specific health and social needs of the residents, as well as characteristics of the surrounding community. For example, if the community is urban with good access to transit, the NORC-SSP might not focus as much on transportation, as if it were in a suburban neighbourhood where a driver's license is required to get by. Examples of services include:

Social services: help accessing benefits and services; social opportunities; life long learning; telephone check-ins; volunteer opportunities for seniors.

Health services: medication management; monitoring of chronic conditions; communication with client's circle of care; advocacy and referrals; short term assistance upon return from hospital.

Structurally, NORC-SSPs are public-private partnerships that unite residents, with housing entities, community groups, health and social service providers, and government funding. Governance is typically shared among partners from each stakeholder group, and most importantly, the residents. The basic organizational structure:

The Lead Agency: oversees budgeting, operations and service delivery. Responsible for raising funds, reports to advisory board

Health partner: Nursing services that typically consist of health promotion, medication management, health monitoring, flu shots, and communication with primary care or family as required. Health supports generally do not include personal care or wound care.

Social Service Partner: Social work supports and case management; connecting clients with benefits and entitlements; providing mental health supports; monitoring health changes; checking home environment for safety.

Housing Partner: Building management provides in-kind assets including room for recreational activities, administrative offices, and cash contributions to the budget.

Community organizations: local groups from the local community may provide assistance with transportation, friendly visiting, errands, and medical escorts.

Resident Advisory Committee: solicits inputs from senior members in the community, and brings these voices back to committee meetings where ideas for activities, events and actions are discussed and planned.

Advisory Board: Includes representation from all constituency groups

NORC-SSPs encourage civic engagement and offer empowerment by providing opportunities for residents to participate in the governance and operations of the program. In smaller settings this may be a one vote per resident governance structure, and in larger buildings, residents may be elected to a resident board or have representation on the advisory board alongside partner organizations. NORC-SSPs recognize that seniors themselves have much to contribute to the communities in which they live. There is a belief amongst proponents that they help expand our cultural notion of what older people are capable of, by transforming seniors from simply 'recipients of care' to active participants in shaping their community.

BENEFITS

Affordability

Low cost to government as they benefit from economies of scale while honouring the desire to age in place. Generally offered at no cost to residents. Additionally, community resources are leveraged in the building and individual seniors continue to pay for their own rent and food bills, thereby lowering the overall cost of the initiative. If widely adopted and implemented in Canada, these programs have the potential to provide enormous system-wide savings for taxpayers and the government.

Moving Not Required

Many seniors have a strong desire to remain in their own homes and in the communities that they have known for years. NORC-SSP wraps supports around seniors where they already live.

Integrated Services

The NORC-SSP model has the potential to strengthen age-friendly communities, as they can act as a hub that brings together residents, volunteers, community agencies and health and social services into an integrated system of support.

DRAWBACKS

Does not necessarily prevent isolation

Seniors in NORC SSPs that do not have services directly in the building may still experience social isolation. Especially if they are experiencing mobility changes and are not able to get to the NORC Centre.

Accessibility

If buildings are older, or designated low-income housing, they may need a significant amount of capital investment to build in accessibility features to support seniors aging in place.

May change intergenerational make-up of the building

NORC-SSP programs may draw more senior residents to the community, slowly changing the demographic make-up to skew towards a more senior population. Many seniors may not like this, as an intergenerational and mixed tenancy may be seen as keeping the community vibrant.

CO-OP VILLAGE NORC

NEW YORK CITY, NEW YORK

Co-op Village NORC is a supportive living organization that provides health and social services to a naturally occurring retirement community on Manhattan's Lower East Side. It is embedded directly in the community, which spans 4 housing co-operatives, 10 city blocks, and 20 high-rise buildings.

Co-op Village is an example of a horizontal or neighbourhood NORC – a cluster of apartment buildings located in a neighbourhood with a high proportion of seniors. That density is capitalized on to deliver targeted, more efficient, population-based supportive services by organizations from within the surrounding community. There is a social services partner, a health partner, and various other community agencies that chip in with friendly visiting, transportation and exercise.

The lead agency for Co-op Village is Educational Alliance, a social service organization that has been in the neighbourhood since 1889. Their goal is to keep residents stable and living independently in their own homes, by building trusted relationships with residents before a crisis hits. They see themselves as a social service agency that provides a health component, but are not a formal health care organization per se.

Co-op Village members span ages 60 to 108, and are made up of residents that live within the 4 co-operative housing entities that make up the NORC: Hillman Houses, Amalgamated Dwellings, East River Cooperative and Seward Park Cooperative. In addition to in-kind support from partner organizations, there is a core group of 7 full-time employees: three social workers, who provide case management and navigation support through home visits and telephone support, as well as two visiting nurses who do health monitoring and medication management, a director and an office manager.

Volunteer partners, including local community agencies and senior residents, run additional social and recreational programming in the NORC-SSP common space. Over 50% of programming is developed and run by the senior residents themselves. The cost of these services is free of charge to members.



fig. 24 / Co-op Village NORC is a join effort by four housing cooperatives on the Lower East Side of Manhattan.

CORE ELEMENTS OF CO-OP VILLAGE MODEL

Eligibility

Residents of Co-op Village who are older than 60 years old are eligible. There are no criteria regarding functional status or income to be a member. The majority of clients are over 85. To qualify for state funding, 50 percent of units in a vertical NORC need to have one occupant who is elderly, or 2,500 residents who are over the age of 60. Additionally, a majority of the residents are low to moderate income, as defined by the U.S. Department of Housing and Urban Development.

Funding & Costs

Co-op Village is free to residents of the Co-op Village buildings who are over the age of 60. Services are paid through Co-Op Village's annual budget, which sits around \$600,000 annually, and includes in-kind contribution from community partners. The rest of the budget is funded through cash contributions from each of the four co-operatives that make up Co-op Village, as well as through the New York State Office for Aging's NORC program and New York City Office for Aging's aging in place initiative.

In New York City, where the model has been running for close to two decades, a NORC is able to apply for state and municipal funding to run supportive service programs if they meet density and age criteria. Many groups in NYC rely on both levels of support, in addition to in-kind community support and philanthropic grants, to meet their budgets. As an example, New York State grants are provided through the New York State Office for Aging, which gives up to \$200,000 annually over a 5-year term. A key stipulation of this grant is that the NORC-SSP must find matching funds equivalent to 25% of the budget, but that amount can be a mix of cash or in-kind support. In-kind support might be in the form of space contributions from the housing partner for administrative offices or programming, nursing hours from a health partner, or philanthropic donations. New York State Office for Aging (NYSOFA) does not have a set calculation of rate per person guidelines, as needs, health status and median age may vary greatly between communities.

"You can't compare NORCS to NORCS – some are small with one hundred clients, even though there are more seniors in the area. Some NORCS have thousands of clients, and serve a community that may have six or seven thousand residents. Costs vary depending on which services are in-demand. If a NORC has high needs, there is a higher costs per client. Some NORCS are also better at getting volunteers to lead programs or finding additional funding. There is no set dollar amount per NORC client." - Jennifer Unser, Aging Services, New York State Office for Aging

Supportive Services

There are multiple pathways for membership admission. It can be self-referral or from family, friends, or physician; or through the emergency department at the hospital or from building management. Being open to multiple pathways lowers barriers to access. Services include:

- *Health / nursing services*: blood pressure monitoring, medication monitoring, diabetes education, blood sugar readings, calling primary physician on client's behalf, advocating for client,
- *Social Services*: Social work, care coordination, system navigation, friendly visiting, telephone reassuring, limited transportation, making sure benefits and entitlements are in place (food stamps, Medicaid and Medicare), medical alert bracelet, home assessments, education and recreation exercises, fall prevention, social classes – brain aerobics, current events, documentary club.

Governance

Educational Alliance is the lead agency and acts as the backbone of the organization, overseeing budgeting, operations and service delivery.. They are accountable to an advisory board made up of representatives from partner organizations and residents. Co-op Village also has a Planning Committee and Seniors Advisory Committee made up of residents that meet quarterly to put forth new ideas and suggestions.

Key Partnerships

At its core, Co-op Village NORC is a consortium of partners working together to build a safety net for the seniors who live in their buildings: Educational Alliance is the lead agency and acts as the backbone of the organization, overseeing budgeting, operations and service delivery; Visiting Nurse Service of New York is the health partner offering in-home nursing services; Mount Sinai Beth Israel Hospital provides in-kind nursing hours; United Jewish Council provides medical transportation; and Henry Street Settlement provides friendly visiting, help with grocery shopping, and accompaniment to doctors appointments.

IDENTIFIED NEEDS AND GAPS FILLED BY THIS MODEL

- Isolation
- Anxiety
- 'Precarious support'; insecure, uneven or unreliable care in the home



A DAY IN THE LIFE

—
*A NARRATIVE OVERVIEW
INCLUDING QUOTES,
AUDIO DOCUMENTARIES,
AND PHOTOGRAPHS.*



fig. 25 / Lower East Side, Manhattan.

The area around Co-op Village bears the markings of an era gone by. This is the neighbourhood where in the early 1900s Jewish immigrants packed into the now-famous tenement buildings; sometimes nine families to a floor, with one bathroom shared between them. But as the neighbourhood evolved, it came to embody middle class family life. Residents were teachers, garment workers, postal workers, and other union and city employees.

It was in the late 1950s and early 1960s that the garment union pressed for better accommodation for its workers, and many of the old tenement buildings were torn down. They were replaced with the co-op buildings that now make up Co-op Village NORC. The tall, over 20 story brick buildings are fairly similar in look and feel, and present an imposing wash of utilitarianism and democratic living. Many members of Co-op Village are original tenants who have been living in the buildings since they were first built. They have grown up here, raised families here, and are now choosing to remain here aging in place, often alone.

The tight knit community that formed through the co-op structure managed to keep the area a cultural enclave for decades, but in the mid-1990s many of the co-ops changed their rules to allow residents to sell their units at market rate. This paved the way for the gentrification the area is seeing today, as New Yorkers clamor to buy apartments at a fraction of the cost of nearby neighbourhoods. There are now ‘hipste’r cafes and new condo construction going up alongside old Jewish bakeries and synagogues, and an influx of people from diverse backgrounds: young and old, Latino, Black and Asian.

Depending on who you ask, Co-op Village is either the first or second oldest NORC SSP to ever exist. It is run by Educational Alliance, but the idea for the program actually came from the co-op boards themselves after noticing their aging demographic, and issues showing up due to lack of resources. According to Don West, who was the board president for Seward Park Co-op at the time Co-op Village was formed, they started to notice that they had a lot of seniors living alone, and that many were not doing so well:

“We all had the same issues with elderly people. Most of it was floods, but we had hoarders too. And we had people not taking their drugs or walking around in their bathrobes in the lobby. So we knew we had issues, we had gotten feedback from our own managers on site. And then we figured we have to address this - and the answer was not to take people and get them out, but to help them at home.” – Don West

A NEW MODEL

His idea of bringing health and social supports to senior residents living in the co-op building was similar to one that had been percolating amongst a few organizations in New York City at the time, namely by Anita Altman at the United Jewish Appeal and Fredda Vladek at the United Hospital Foundation. They called it a Naturally Occurring Retirement Community with Social Services Programs. This idea resonated with the other Co-op Village boards, and so relatively quickly they were able to gather together funds to help support the joint initiative. They found early support from a Robert Wood Foundation grant, and also began lobbying the city and state Offices for the Aging to help secure additional funding, which continues until this day.

“The argument was keeping people in place. Seniors are people like everybody else, and it’s the wrong thing to do to push them aside. In most cases they helped build the country, and to keep the economy going and so on. And so to take these people who are now in their retirement age or maybe not as healthy or frail, and take care of them in a way that is respectful.”

– Don West

FLUIDITY / FLEXIBILITY

The offices for Co-op Village NORC are located on the top floor of a small four-story building that also houses a bank, a language school, and a few other community service organizations. The space was donated by Seward Park Co-op as part of their in-kind funding agreement to get the NORC SSP off the ground.

On the day I visited the Co-op Village offices, there were a dozen or so seniors hanging around the main space. Four private offices dotted the perimeter, reserved for the organizations 7 full-time employees: three social workers, two nurses, a director and an office manager - although many of them were out on house calls. A large, open space was being used for card games, but could have easily been organized for any number of the center's social or recreational activities.

Looking at the events calendar, I noticed there were standard 'seniors activities' on the board, including chair yoga, karaoke and knitting groups, but there were also others that seemed a little divergent: documentary club, guest lectures, current events groups. Bonnie Lumagui, Director of Co-op Village, told me that they regularly revisit the schedule based on seniors' feedback, and that 50% of the classes are organized and run by the seniors themselves. Talking with her, it became apparent that this is partly out of fiscal necessity, but also as a way of partnering with seniors.

Part of the NORC SSP approach is to tailor services and activities locally, and to have programs reflect the needs and desires of residents. For Co-op Village this approach is not only sensible from a business standpoint, but they see it as an important part of building a supportive care model: having seniors involved in the running of the NORC helps build a sense of purpose, community and ownership, and impacts health, wellbeing and longevity.

While Bonnie and I spoke about the

organization's operations, it became clear to me that 'fluidity' was one of their core beliefs. According to Bonnie "*Senior's are humans who are constantly evolving. If we are too rigid in what we do, we might not be able to meet their needs*". In her mind, seniors supportive living programs need to have the mandate to be able to be responsive and agile, and to have the self-directed freedom to pivot and shift offerings, schedules, and intensity of supports based on the real-time needs of the seniors they serve.

'A SOCIAL SERVICE ORGANIZATION WITH A HEALTH CARE COMPONENT'

Another theme that came up while talking to members was the negative role that anxiety plays in their life, and how much 'NORC' - as Co-op Village is affectionately known - helps in addressing it. Many residents live alone; many have mobility challenges. Their children may or may not be close by to offer help and companionship. They spoke about the importance of just having somewhere to go - where you'll be recognized and given a warm reception, and maybe even a hug.

LISTEN TO HELEN'S STORY:

www.seniorsocialliving.com/helen

Co-op Village sees themselves as a social service organization with a health care component, not the other way around as is often the case in seniors supportive living programs. To them, health and social work go hand in hand. According to Ned Lustbader, one of the social workers at Co-op Village, one of the consequences of social isolation is that there is too much time on one's hands to think about things



fig. 26 / Don West was Co-op Board President at the time Co-op Village was started in the 1970s.



fig. 27 / Co-op Village's buildings were constructed after the area's now-famous tenement buildings were torn down in the 1960s. Many original residents are still living in the area, and now belong to the NORC.

and get all worked up. There is also no one there to help distract them from unwanted thoughts. He sees part of NORC-SSP's roles as just be there to lift the spirits of members and ease fears around aging. In his experience, this small action helps people stay at home in peace.

In many ways Co-op Village acts as a professional or surrogate family for residents who are alone, but one that is well-versed in what is available in the community, or how to help support seniors staying in the home when functional status declines.

As I immersed myself in Co-op village it became clear that there were two sets of NORC members: ones who were mobile and wanted a destination to travel to everyday; and another set who were more frail or suffering from depression that needed someone to come to them. Co-op Village has structured their organization for both. At the centre, seniors run programs and socialize with one another. For the homebound, social workers stop by, and volunteer residents call to check-in to make sure residents are alright. For many seniors, this is the only social contact they will have all week.





*fig. 28 / Ned Lustbader, social worker,
out on home visits.*



*fig. 29 / Mr. Hyman Segal, 100, found a doctor who does home
visits through Co-op Village NORC.*



fig. 30 / Neal Goldstein says he relies on Ned to help him manage all of his 'dealings with organizations', from signing up for food stamps to paying his rent on time.



fig. 31 / Helen Baker has lived in the area for her whole life. She now runs the popular current events class at Co-op Village NORC

INGREDIENTS TO SUCCESS AT COOP VILLAGE

1. Fluidity/Flexibility

In order to successfully meet the needs of a wide diversity of ages and personalities, organizations must continually engage with senior residents and their changing needs. Having an organizational mandate that allows for changes to frequency, type and intensity of services is required in order to support people to stay in their own homes.

2. Focus on Navigation

Old age is a stepwise process, that most people are ill prepared for and lack sufficient knowledge to navigate services and appropriate support. Co-op Village can act like a professional family in that they build strong social bonds with clients who are homebound or isolated, and help connect them with appropriate services.

3. Leverage Existing Community Resources

Co-op Village NORC is a partnership initiative that leverages existing community resources that are geared towards seniors and brings them into the buildings where they reside. Duplication of services is avoided and costs are saved through service integration between local partners who have similar mandates: to help seniors at home.

OBSTACLES TO IMPLEMENTATION

Strong Leadership Required

A strong leader is needed to manage this multi-stakeholder initiative and energize senior residents. This leadership needs to come from inside the community coalition, and can be from residents members, housing partnership, health partner or social services agency partner.

Difficulties with Provider Integration

NORC-SSP programs presuppose an integrated service delivery that involves multiple agencies, which may be difficult to negotiate. Participating providers must be willing to work in partnership under one umbrella. Partners share responsibility for the program's success.

Willingness to Partner with Senior Resident

Program success depends on provider's ability to honour the needs and desires of seniors, and to work with them as equal partners.

MODEL 4: VIRTUAL VILLAGES

The Virtual Village model is a community-driven approach to supportive living that aims to help seniors stay in their own homes for as long as possible. Services are delivered in the home through a robust network of volunteers gathered from the immediate community, and are organized by a central coordinator. The central coordinator may be paid or a volunteer. The goal is to respond to the needs of seniors through a “one-stop-shop” approach that delivers flexible, personalized support.

The Village concept emerged in 2001 with the founding of Beacon Hill Village by a group of seniors residing in Boston, Massachusetts. It has since grown into a national Village-to-Village Network, which provides expert guidance, resources and support to help communities. The Village Network has 251 member organizations that serve approximately 25,000 members. The concept is very popular in the United States, however there has only been one attempt in Canada so far.

As with many emergent, community-driven programs, there is no set way of organizing a virtual village. As one director said to me “if you’ve seen one village, you’ve seen one village.” Villages, like NORCS, are bespoke to the community they serve. Age of residents, geographic conditions, support needs, and availability of volunteers are factors that greatly influence the look and feel of villages. However, there are some general characteristics that are shared. Residents sign up to become members. In most cases, they pay an annual membership fee, and most offer varying rates depending on whether the services are for individuals or couples.

Membership provides access to on-demand services such as homemaking, transportation, companionship, and grocery delivery, light home repairs, tech support, dog walking, and social activities, depending on what the community of volunteers is able or willing to provide. Volunteers from the surrounding community fulfill the majority of service requests. When a specialized skill is required, villages may engage paid private services or they may simply direct seniors to a list of reputable services providers that have been vetted by the membership.

Volunteers are the backbone of the Village model. Villages rely on a large pool of volunteers that are made up of neighbours in the surrounding community. In many ways, the village model is an attempt to have the community wrap around it’s seniors; to help out with all the little things they either cannot do or cannot afford to do themselves. The neighbour-to-neighbour approach also fosters a feeling of being valued by the community.

Volunteers are mostly retired seniors supporting older seniors who are not as mobile. Residents organize regular events and activities to promote community building. Involvement allows seniors to draw on new interests and hobbies, and relieve social isolation. Volunteering provides seniors with physical, emotional and social benefits, as well as overall empowerment. Volunteering can also bring about a sense of community and mutual support among members.

Additionally, many virtual villages negotiate bulk-discounted rates with local stores and service providers that can be accessed by care coordinators or the seniors themselves. By pooling their money, senior members benefit from the buying power and discounted rates afforded to a larger group. Services are less costly to members than if they were to procure things on an individual basis. Membership fees vary from village to village, but seem to average about \$500 per year, and most villages offer subsidies for people who cannot afford these costs.

*IDENTIFIED NEEDS AND GAPS
FILLED BY THIS MODEL*

- Transportation
- Lack of Resource Knowledge
- Difficulty maintaining a home on one's own

BENEFITS

Affordable

Virtual Villages are relatively low cost to members. They average around \$500 per year for members, and most provide subsidies or wave costs for low-income members. Groups take advantage of bulk purchasing to negotiate discounts at local stores and service providers.

Moving Not Required

The village model also allows older adults to remain in their original homes and communities without relocating.

Reassurance of Community of Support

For some members, knowing that volunteer neighbours are providing the support gives them a sense of reassurance; that they are still valued by society.

DRAWBACKS

Does not necessarily prevent isolation

The amount and quality of connection a member receives is reliant on the connection they build with volunteers. Some villages limit the amount of service requests any one member can make.

Reliant on Volunteers

Volunteers provide more than 90% of the services. The availability of support is largely dependent on the amount of volunteers the organization can attract and keep. Available services are dependant on what community members are able and willing to do.

Lack of Formal Connection to Professional Supports

Virtual villages are mostly staffed by local community volunteers, and as such do not have any formal connections with health or social services. However some villages are attempting to change that. Avenidas Village in Palo Alto, California, has created partnerships with two local hospitals, including putting members personal health information on a portable, key chain flash drive. (New York Times, Gustke 2014)

VERDE VALLEY CAREGIVERS COALITION

VERDE VALLEY, ARIZONA

The Greater Verde Valley is a large, rural area located in central Arizona. It sits high atop the Colorado plateau, surrounded by aspen trees and red rock mountains. The area itself is a de facto naturally occurring retirement community, with seniors flocking to the region from all over the United States to take advantage of the warm, dry climate.

The Verde Valley Caregivers Coalition (VVCC) is a community-based non-profit organization that provides supportive services to older adults in the region who need assistance with maintaining their independence and quality of life at home. It is one iteration of a virtual village: a hyperlocal community organization that provides low cost help to seniors through a large network of volunteers.

VVCC serves most of the Verde Valley, an area that covers over 700 square miles and a population of 70,000, 35% of which are over 65 years old. That density jumps to 60% over 65 years old in the region's main hubs of Sedona and the Village of Oak Creek. Recent data shows that the average age of Caregivers' clients is almost 90 years old. Sixty percent are living in their last 3 years of life, and 50% are living at or below the poverty line.

Given that Sedona is a well-heeled resort town with a high volume of tourists, this seems surprising. However, according to Executive Director Kent Ellsworth, beneath the veneer of picturesque Sedona, there is a lot of need in the surrounding communities, namely lack of transportation and support systems.

VVCC does not provide health services. Instead they focus on providing access to care and assistance with addressing seniors' social determinants of health. In their words, they pay 'a lot of attention to the activities of daily living' - ensuring that members are ok with mobility; that they are safe in their home; and that they are finding solutions to help them remain living independently in their own homes for as long as they choose. Since the majority of their clients live alone, simply providing a place for them to reach out to, no matter how big or small the concern, is a huge help.



fig. 32 / Verde Valley Caregivers Coalitions covers an area of over 700 square miles in Arizona.

VVCC serves 2,300 seniors annually on a budget of \$600,000 per year. Funds are raised through large foundations and grants, with some donations coming from local community. There are two full-time care coordinators, an executive director, and a part-time administrative assistant on staff, and over 350 volunteers. Last year volunteers provided 70,000 hours of service, 30,000 rides, and drove over 300,000 miles.

Verde Valley Caregivers Coalition services are free of charge to its membership. There is no income threshold for becoming a member – instead it is based on reported need. They accept referrals from multiple channels, including family members, community agencies, social workers, adult protective agencies, and seniors themselves.

In many ways, the Caregivers model can be seen as a pay-it-forward system that makes use of the unmet needs and untapped capacity of retirees to address the gaps in care experienced by less mobile, more vulnerable seniors. It also helps the organization build a low cost, flexible service that can quickly respond to the changing needs of its members over time.

CORE ELEMENTS OF VERDE VALLEY CAREGIVERS COALITION

Eligibility

Seniors 60 and older and individuals with disability who are unable to drive due to health conditions or advanced age living in the areas of Sedona and the Verde Valley are eligible for services.

Funding & Costs

Services are free to the 2300 members of VVCC. The annual budget of \$600,000 per year is raised through large foundations and grants, with some donations coming from local community. Verde Valley Caregivers has over 500 individual donors.

They hold a Professional Liability and Specialized Liability insurance policy for volunteers, which has a \$2 million aggregate that covers volunteer drivers above their personal auto insurance. They also have Theft Coverage for staff and volunteers. Annual costs are \$14,000.

Supportive Services

Their 'DO WHATEVER IT TAKES' model includes, but is not limited to, fixing leaky faucets, repairing A/C systems, changing light bulbs, taking a pet to the veterinarian, friendly visiting, providing medical alert bracelets, yard cleanup, and grocery shopping. However, transportation remains by far their biggest service call.

VVCC tries their best to meet each and every service need themselves or strives to find a community partner who can do so. It is a warm transfer and handoff – members are not left by themselves to figure it out how to connect with services.

Governance

A board of directors and an executive director oversee the organization, with regular input from staff, members and volunteers. The Board of Directors play a big role in governance and setting policy, as well as fundraising through the cultivation of major individual donors. There is also a Finance Committee, Development Committee and Nominating Committee.

At least one senior serves on their board at all times, and several board members also provide volunteer services themselves. Other ways for seniors to give feedback is through regular surveys and requests for feedback on prior services through the call centre.

Key Partnerships

Verde Valley Caregivers Coalition is a partnership model that leverages multiple existing resources. Key partners include: volunteers, local and regional governments, faith communities, primary care providers, and social services and community agencies. Partners meet once a month. VVCC see ongoing stakeholder engagement as an important factor in their success.

Of course volunteers are a key partnership. They get about 60-100 new volunteers signing up every year and currently have 340 volunteers. To recruit they do upwards of 12-15 presentations each year at service clubs, churches, and women's groups. They put notices in newspapers, print media, and always tell their volunteers *"the next best thing you can do for us is to tell your friends about us, and tell them to come volunteer"*.



A DAY IN THE LIFE

*A NARRATIVE OVERVIEW
INCLUDING QUOTES,
AUDIO DOCUMENTARIES,
AND PHOTOGRAPHS.*



fig. 33 / The Greater Verde Valley, Arizona

On the day I visited VVCC's office, there were multiple, ongoing discussions happening between the two full-time coordinators. They were trying to find solutions to a service request that had come in that day, and needed to talk it over with each other to see what they knew about available community services.

"It's the problem solving centre... it's a lot of really getting to know our neighbours... We talk to them often so we know when they're going downhill. There might be changes where we have to get back out there to see what their needs are, and then sometimes we even contact a family number." – Kim Meller, Operations and Mobility Manager

The majority of Caregiver's members are over 85 years old and living alone. Many are not native to the area, having moved here with a spouse who has since passed away. Adult children live hundreds, if not thousands of miles away. They have few built-in networks to provide comfort. Losing a license in this landscape is akin to becoming utterly dependent on others for the basic necessities of life.

Trips to the doctor's office become challenging to orchestrate, particularly trips to see specialists, who are largely located in urban areas. A ride to Phoenix is over 200 miles round trip, and would cost over \$400 through a private paid service.

FOCUS ON RELATIONSHIPS

A ride from 'Caregivers' is more than just a drive and a wave goodbye. Their offering is a mix of practical solutions and social connection; it's a ride to and from a doctor's appointment with someone who will wait with you in the waiting room and talk with you on the drive home. It's a trip to the grocery store with someone who will reach for items high on the shelf, carry your grocery bags inside, and help you put them away. During the time I visited, I had the opportunity to witness the camaraderie and goodwill that seemed to emanate in both senior neighbors and senior volunteers through the program.

LISTEN TO BETTY'S STORY:
www.seniorsocialliving.com/betty

Knowing where to turn for help is also challenging. As Director Kent Ellsworth points out, "the world is different and continues to change. It can be hard to keep up with resources. 80% of our members don't have a computer, and 65% have no cell phone." Coordinators work in a small call centre in Sedona. They receive over 900 calls per week for anything from finding a lost pet, to requests to go to the hairdressers. They do their best to meet all these requests, no matter how big or small, or seemingly insignificant. In their

view, these are the things that seniors want and need to feel good at home; to sustain them and give them life.

Betty Walker, 88, is a senior neighbor who lives in the small town of Camp Verde. One of her daughters lives nearby, but she is busy often and so Betty relies on Verde Valley Caregivers for support. She is still healthy, although says that she's "having a little bit more trouble with trying to keep my thoughts together and I have more trouble getting around than I used to." She has developed a close friendship with Valloy, 73, one the volunteers. They had both been married twice, and were now single. They had both had the experience of losing a child. According to Valloy, the volunteer:

"It's just strange how that happens. It's like there's almost some kind of force... I think a lot of volunteers find that too. They find that somehow you get matched with somebody, and it's like 'yeah, that should happen'...you have the empathy, you have the knowledge... It just kind of all feeds, and then you grow... a lot of healing."

Betty is used to living on her own, having lived on a ranch on her own for many years. Recently she had a fall in the middle of the night, and was lucky enough to be able to call one of her next-door neighbours for help:

"I really can't tell you just exactly what happened, except that all of a sudden I found myself losing my balance and sliding and falling. I was just completely alone on the floor and I couldn't get up. But I managed to crawl over ...and unlock my door. Then I made

some noises so that my neighbour downstairs could hear it. She came up and called the Fire Department to come get me up. But I didn't go to the hospital or anything, because I wasn't hurt bad. But I was achy and it hurt."

Betty usually only calls Verde Valley if she needs Valloy to pick up groceries for her or prescriptions, or sometimes take her to a party. She's had to give up her truck in recent years, which in this landscape means she has lost the ability to do many of the things to sustain herself on her own. She says Verde Valley is something she can rely on, so that she can maintain her independence.

VOLUNTEER-FIRST PHILOSOPHY

VVCC has made itself attractive to retired health care professionals who are willing to use their existing skills to help support their neighbours in non clinical ways. In the Transitional Care Program volunteer nurses are paired with senior neighbours who are being discharged from hospital. Volunteer nurses visit several times a week, for several weeks, to help them resettle. According to Kent Ellsworth, this program has helped reduce overall readmission rates from 13% to 5% at the local hospital.

"It doesn't necessarily stop the progression of those chronic health conditions - but we've been able to show through data in conjunction with the local health care system, that once the people come to us, they rarely need repeated acute care stays. Their typical habit of going to the emergency department is done."

The 'whatever it takes' model employed by Verde Valley Caregivers Coalition leverages existing community resources and services to make up gaps in care that

cannot be provided by volunteers. They will find a local agency to fulfill the request. This could be a free service provided by another community agency, or a paid service from local providers. VVCC will then coordinate the service on behalf of its member, sometimes sending a volunteer out to ensure everything is done properly and no one is overcharged. In some cases, Caregivers may pay for the service or item themselves depending on budget and need, or else may help the senior enroll in benefits and entitlements that can cover costs.

"We had a fellow who went to the hospital, and he came back and his mobility challenges had gotten much worse during the week that he was in the hospital. And he came home and he couldn't transfer out of his wheelchair anymore, and there was no wheelchair ramp. So what we did was call Habitat for Humanity, and they came out the next day and built a wheelchair ramp for him. So its making the connection with all the other community resources that are available out there."

– Kent Ellsworth, Executive Director

Since volunteers perform the majority of services, the organization has had to develop a robust vetting protocol. This consists of checking for a criminal record, clear driving record, and willingness to set aside time to receive a phone call request. The organization engages in 12-15 presentations a year to recruit new volunteers. They attend service clubs, churches, community gatherings, and women's groups, put notices in local newspapers, and use 'word of mouth' from existing volunteers.

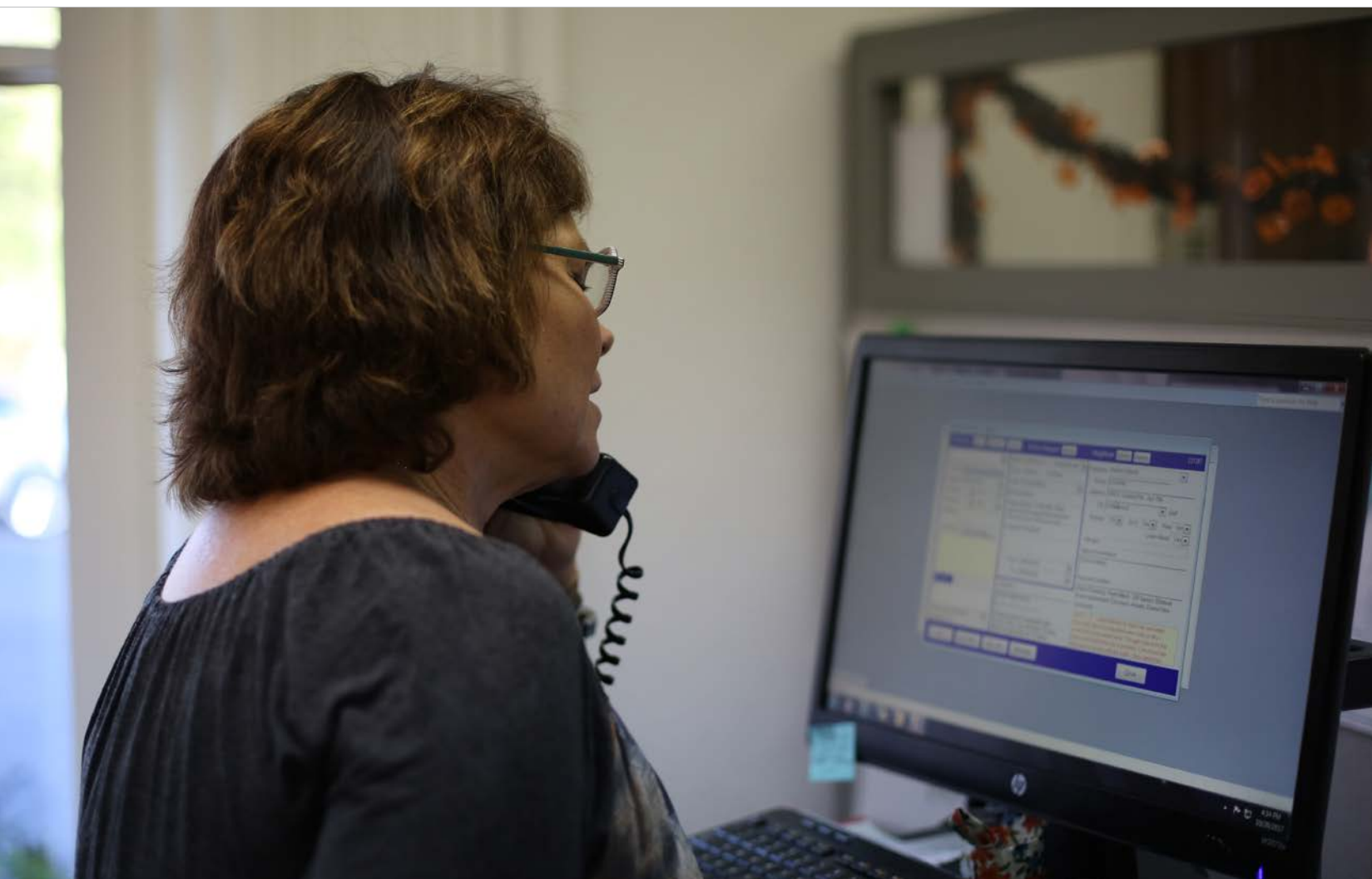


fig. 34 / Kim Meller takes service calls from 'neighbours' requesting help. She says that every day is like a 'Rubix Cubic' trying to make sure everyone gets what they need.



fig. 35 / Tom Brand, 84, volunteer, waits with Betty Davis, 80, 'neighbour', at her cardiologist appointment.

VVCC has made a point of recruiting retired health care professionals who want to continue making a difference, yet want to do so in a flexible, no-obligation environment. Coordinators personally call volunteers until they locate someone who is able to fulfill the request. It is a high touch, time intensive process, which they say makes all the difference in maintaining a volunteer-staffed organization.

Most interestingly, many volunteers are actually seniors themselves. Either younger, retired, or just more mobile, they are looking for something to do to feel relevant now that the structure of work has been taken away. The social connection and opportunity to get to know others in community is also something that appeals to volunteers, who may be experiencing isolation themselves.

For volunteer Tom Brand, 84, keeping busy and having something to commit to in life are keys to aging well in the community:

“After retirement you’ve got to find a new view to put that energy into... you know you work 40, 50, 60, 70 hours a week... And now all of a sudden, all that’s gone. The next day it ends...Life is going to be a real pain in the neck almost until you can find that. I think it doesn’t make any difference what it is either. I mean it can be seeking a new profession. Or it could be just something like - learn how to play golf and this is my goal. But it has to be something you can pour that energy. Otherwise I think you’re going to go downhill.” - Tom Brand, Volunteer

SOMEWHERE TO CALL

VVCC report seeing a tremendous amount of anxiety and worry among its membership. As Kent Ellsworth explained it, the value for members is in being able to get needs fulfilled, but it is also in simply having somewhere to call and ask for help. Their one stop shop approach, with a warm body answering the line, seems to be valuable to members. It is a high touch approach, but one they say is a great benefit to the community at large:

“Fire Chiefs give people, who repeatedly call, our number, and they don’t hear from them again. Many times these ‘frequent fliers’ don’t need emergency services - they are just afraid. They are just stressed. It’s more of a mental health episode, so they call 911...that stress coalesces into a huge amount of fear. [Having somewhere to call] has a real impact on a person’s ability to deal with all the new things that come up living independently in their own homes.” - Kent Ellsworth. Executive Director





fig. 36 / Transportation is the most requested service.



fig. 37 / Betty Davis

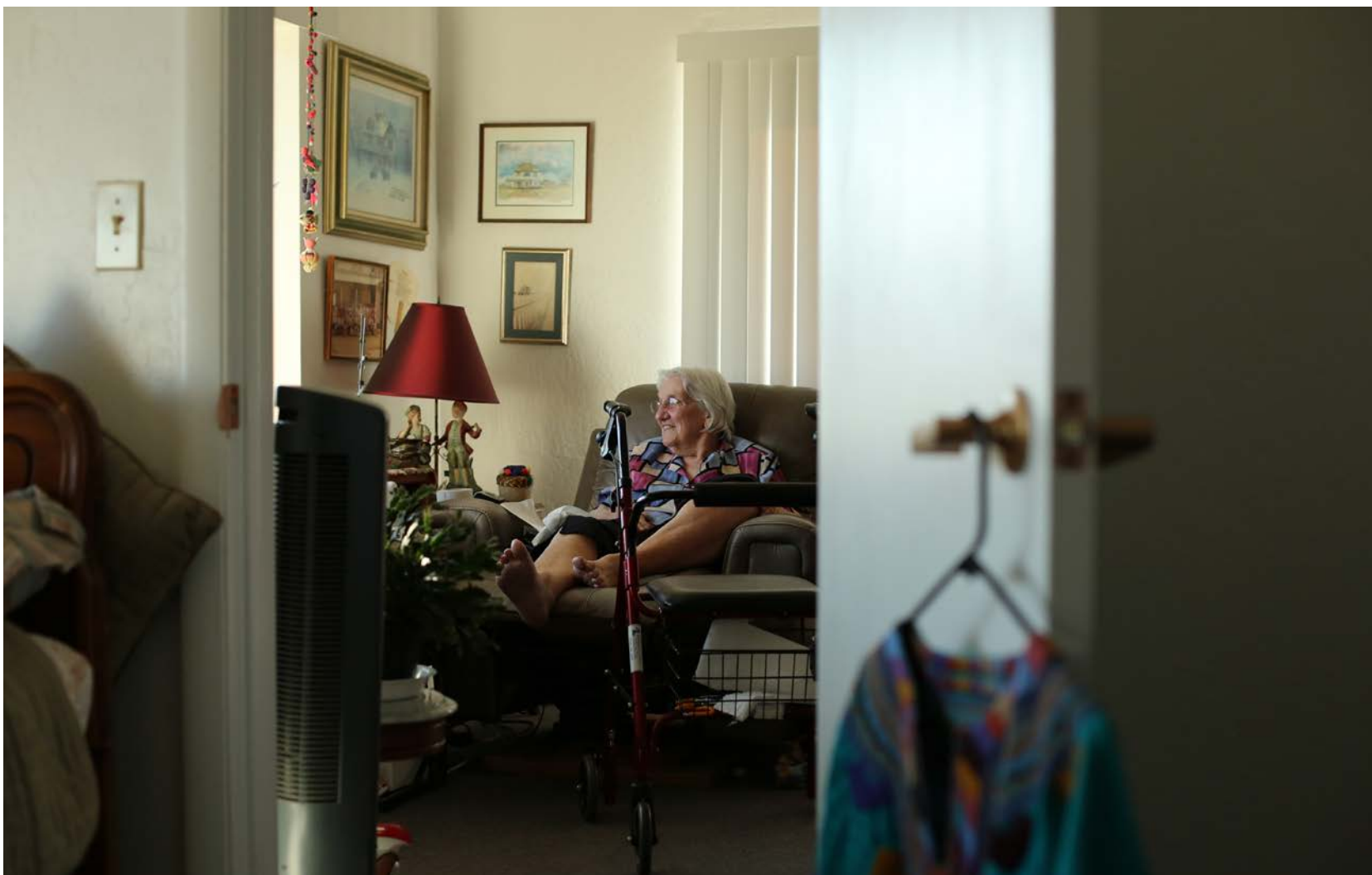


fig. 38 / Betty Walker, 88, lost her license and now relies on a combination of family and Verde Valley Caregivers to bring food and pick up her medication.



fig. 39 / Valloy, 77, visits with Betty once a week and has found that the two women share similar histories.

INGREDIENTS TO SUCCESS AT VERDE VALLEY CAREGIVERS

1. Focus on Relationships

Care coordinators are doing much more than 'just arranging a ride'. They are keeping an eye on members' ability and functional status by maintaining a personal connection. Members report that caregivers' phone calls and visits are often the only human contact they have in a given week. Building consistent relationships with vulnerable seniors helps insure that the number they call in the future if experiencing distress is Verde Valley Caregivers Coalition, instead of 911.

2. Flexible, 'Volunteer-first' Philosophy

One of the unique characteristics of VVCC is their 'volunteer-first', neighbor-to-neighbor approach. Special attention is placed on the needs of volunteers: their skills set, impact goals, personality, and most importantly, their schedules. They feel it is important to offer flexibility and a guilt-free experience to volunteers since most of them are retired, and do not want a fixed schedule. The greater flexibility they are offered, the greater the retention of willing volunteers. The call centre also makes an effort to connect with volunteers to see how they are doing and to prevent burnout.

3. Leverage Existing Community Resources

The organization is lean, focusing on minimal overhead and maximum coverage. By connecting seniors with existing community services they are not tying up their resources and manpower on duplication of services.

OBSTACLES TO IMPLEMENTATION

Funding

Getting commitments that provide 3 years of initial funding is usually a big challenge – the start up time Kent estimates is needed to get an initiative like theirs off the ground. Local foundations, the health system, local governments, key community leaders and local corporate and individual donors can combine to assure both initial and ongoing funding.

Securing a Dedicated Steering Committee / Advisory Board

Getting a highly dedicated steering committee in place is the first challenge. The steering committee needs to have several well-established community leaders. This team identifies partners and develops the organization plan. The steering committee and its partners also need to be able to write a compelling case for support to be able to get the initial funding commitments they need.

Burnout

Volunteer organizations run the risk of participant burnout; extra precautions need to be taken to make sure volunteer staff are not feeling undue pressure or stress.

"To the extent that older people are infirm, isolated, or dependent, growing numbers of older people will increase the burdens on a relatively smaller younger population. To the extent that older people are healthy and involved, they will likely contribute far more to society than older people in previous generations."

- 'When I'm 64'. The National Academies Press, 2006

Reflection

During the course of primary research, it became clear that two distinct groups of grassroots models were emerging: Group A (Cohousing and Homesharing) skewed younger on average and had fewer immediate needs for support. Group B, (Naturally Occurring Retirement Communities with Social Service Programs and Virtual Villages), skewed much older and more frail.

There are several distinctive patterns between these models, which are discussed below. It is important to note that none of these groups think of themselves as 'health care' organizations, even though health is among their top concerns. Rather, they see themselves as extended networks of support that improve health by increasing access to care on one's own terms. These models do not alleviate the need for government home care services. Rather they work alongside them, filling in the gaps where health care does not exist due to service policies, or where informal care is not available or simply does not exist.

In fact, there may be a case to be made that these models reduce the need for public services, as they address many of the little things that can lead to decline or excessive worry that can result in unnecessary trips to the emergency department. However, as these are local, grassroots initiatives, little to no data exist about their impact on system utilization. Perhaps this is an area of opportunity for future research.

As a whole, these groups excel at providing a mechanism, or rather a container, in which neighbour-to-neighbour exchange flourishes. In most of these case studies, those participating are strangers – sharing only a mutual geography or an affinity to a community ideal. However this 'neighbourliness' seems to be solving a lot of issues that can lead to decline when older seniors are left to fend for themselves: assistance with home maintenance, emotional support, access to nutrition, system navigation, transportation, security, and mental stimulation.

And it is not just the direct support that is health enabling. The seniors I interviewed spoke of the value they feel in 'being part of something'. The very act of participating in the design and running of these initiatives was providing a sense of purpose and meaning in their lives, at a time in life where those two things are usually lacking. Whether organizing a debate club at the local NORC centre, or joining the landscaping or facilities team in cohousing, active participation was seen as a key ingredient to aging in place across all groups.

And while 'participation' can simply be read as a way to pass the time, the seniors themselves explained to me that it was much more than simply another activity – it was the sense of being valuable to the community, and that sense of purpose was tied directly to a feeling of agency and vitality. Meaning and mattering, self-determination, mental stimulation and social connection were all identified as ingredients to thriving in the community.

Group A: Homesharing and Cohousing

The two iterations of Cohousing and Homesharing that I visited for this project are small in scale with just 41 and 4 members respectively. The central idea in both is that seniors will have a better chance of being able to age in place if they can access a large network of informal supports.

In these two cases, the community network lives right on the same property, and in the case of cohousing, in the same house. Seniors supporting seniors minimizes the burden any one family caregiver may experience, and can lessen the need for government systems. It opens up a wider pool of knowledge from which to draw, and allows for an increased amount of social contact. It remains to be seen if this does in fact lessen the load on family caregivers or public services. Members at Harbourside Cohousing and WHIM are on the younger side of elderhood, and not yet experiencing the kinds of decline that requires more intensive care service. However considering that as many as one in three seniors could be living outside of long-term care if they had adequate community supports, these models are attempting to bridge those gaps in a low cost capacity.

Intimacy

Homesharing and cohousing are more intimate models of care than NORC-SSP or Virtual Villages. Residents live in closer quarters. And although they still have private spaces, the infrastructure is designed in a way to encourage informal interaction and community building. Ample communal space is meant to supplement smaller personal space and is intended for use on a daily basis.

Strong social bonds are needed as these models rely on the goodwill of neighbours to provide care to one another through potential sickness and age-related disability. Understand that mutual support is the social technology that makes this model work, these groups seemed dedicated to finding ways to build trust, intimacy and genuine friendship where it feels natural. The backdrop being a desire not to burden adult children, these models are trying to address gaps that exist in publicly available services, and the income needed to pay for private care in the face of increased longevity and costs of living.

Self-Determination

The Homesharing and Cohousing models afford members a high degree of personal agency and control over the decisions that affect their lives. Seniors are actively responsible for planning and running their own communities – from finance and legal, to setting community policy, to arranging for roof repairs, to delivering mutual support.

These models varied in terms of affordability, with homesharing being quite inexpensive, and cohousing being quite expensive due to the ownership structure. However, Andrew Moore who started the Canadian Seniors Cohousing Society is convinced that cohousing does not need to be an ownership model, and is currently running five pilot projects to see how the cohousing model can be scale in various settings, including: retrofitting an existing condo; a faith-based community; a housing co-op; a rural area; and an affordable/supported rental building.

Lastly, although cohousing is a higher cost endeavor, like homesharing, there are savings to be had through bulk purchasing and sharing the responsibilities of home maintenance and repair amongst multiple people.

Across the board, everyone I spoke to in Group A were terrified of having to go to into institutional care. To hold this off, they both have built-in caregiver suites for times when members may need more extensive care, for an extended period of time. This could be after a hospital stay or for palliative care. They are both actively working on care protocols that outline what kind of personal care members will give to other members when the day comes that they need more help. Both groups told me about the need to balance the needs of individuals with the needs of the group, and were focusing on not only what people are willing to give one another, but what they are willing to receive. It seems to them that asking for help is one of the biggest challenges of growing old. Building a secure network of informal support that has long histories and closer ties helps ensure that people will both reach out before there are problems, as well as increase the likelihood of providing care to a dear neighbour in a time of need.

Homesharing & Cohousing

Benefits:

- Autonomy / Self-Determination
- Built-in network of mutual support
- Economies of scale / cost savings

Drawbacks:

- Decreased Privacy
- Reliant on community cohesion
- Downsizing can be hard for some
- High Cost (Cohousing-only)

Group B: NORC-SSP and Virtual Villages

The second grouping of models includes Naturally Occurring Retirement Communities with Social Service Program (NORC-SSPs) and Virtual Villages. The examples I visited for this study catered to an older clientele, who on average, have higher rates of chronic health conditions and more difficulties with mobility.

The average age of Verde Valley Caregivers clients is close to 90 years old; Co-op Village’s clientele averages around 85. It is beyond the scope of this research to ascertain whether this is the case in general with these models of supportive living. However, being that it was the case in this research, it did provide some interesting insights into what is possible, or seems possible, for older seniors to accomplish without outside help.

No Moving Required / Services Come to You

The main value driver of these models is they delivery services to seniors in their own homes, and do not require seniors to move. For many this is desirable, as downsizing is not always desired, nor is leaving the community in which they have lived, sometimes for decades. Both models attempt to wrap services around seniors rather than have them go anyway.

As with Group A, they do not provide 'health care' formally. Programs and services target the social determinants of health, and focus on providing access to health care through care navigation and transportation. While NORC-SSPs tend to have a professional staff of social workers and visiting nurses, Virtual Villages are largely volunteer-run and do not have direct access to health care providers. Some make efforts to partner with health systems and integrate care through providing a warm transition for members to and from the hospital, however many seem to be more local, grassroots models with little connection to outside systems of care.

Affordable

In both examples, eligibility is not related to ability level. Services are offered to any senior who identifies as needing support in the catchment area that they serve. Most NORC-SSPs are provided at no cost to members, with funding coming through a mix of government aging in place initiatives or community contributions. Virtual Villages run on a membership model, with an average rate of \$500 per year, and most providing waivers for those who cannot afford it. At Verde Valley Caregivers Coalition, membership is free of charge, as 50% of their clientele are living at or below the poverty line. NORC-SSPs tend to focus on seniors with low to moderate incomes, while virtual villages have popped up in many different communities, and the first model was started in the wealthy neighbourhood of Beacon Hill.

While it could be argued that wealthier seniors can afford to pay for private services, my experience through this research suggests that there is a different kind of value that is bestowed when seniors knew that it was their neighbourhood rallying to keep them healthy of their own accord. They were not being forgotten. They do matter. Besides, as one senior pointed out during the study, old age hits everyone at some point. If family members live hundreds, if not thousands, of miles away, and age-related mobility sets in, so does social isolation and all of the health consequences that go along with it.

At Co-op Village, many of their members were occupying an in-between space, where they were too rich to be eligible for Medicaid, and too poor to afford paid services. One of the gentlemen I interview was living on a thousand dollars a month, just a bit over the \$900 threshold to receive Medicaid and the home help it offers to low income seniors. In a way, this gap mimics the one we have in Ontario, where you either need to have very high needs or a very low income in order to receive an adequate amount of home care support.

Self-Determination

Both the NORC-SPP and Virtual Village I visited had large rosters of clientele. Co-op Village was serving over 2000 seniors, and Verde Valley Caregivers Coalition had 2500. They also served a broad catchment area. Perhaps for this reason, they also tended to have a more traditional governance structures, with an executive director and board of directors helping to keep the organizations going, as compared to the self-run models of cohousing and homesharing.

Seniors themselves had less direct control over how the organization was run in these examples. However, there was an active attempt to partner with seniors. At Co-op Village, seniors develop and run over 50% of the programming and are encouraged to do so. At Verde Valley, seniors make up the bulk of the volunteer base. In both examples, the advisory board is required to include senior residents.

Continuous Care

Verde Valley Caregivers Coalition functions like a one-stop shop, where seniors have one number to call to find support. A warm body answers the line, and works to find a neighbourhood volunteer who is available to fulfill their services request. Since they have a roster of volunteers that is over 300 people, they are usually able to manage. When service requests come in that are beyond the expertise of their volunteers, they will connect with other community providers who offer the services. In some cases they will make the arrangements for the service provider to go to the senior, and they will often send out a volunteer to help ensure that the senior feels comfortable or is not taken advantage of. It is a high touch approach, which they say works well for them keeping an eye on the health status of their membership.

At NORC-SSP, high needs members are assigned a social worker that works with them directly. They will help assess and connect the senior with any services they need, or with help in filling out the necessary paperwork to access it. For seniors who are more mobile, the NORC Centre acts as a community hub, where staff has an open door policy and greet you by your name.

Homesharing & Cohousing

Benefits:

- Affordable
- No moving required
- Focus on bringing care to seniors where they already live and system navigation

Drawbacks:

- Do not necessarily prevent social isolation
- Reduced control over organizational decision-making

	Continuous Care	Cost	Self-Determination	Intimacy
Homesharing	High	Low	High	High
Cohousing	High	High	High	High
NORC-SSP	Medium	Low	Medium	Low
Virtual Villages	Low	Medium	Medium	Low

Key Insights and Emergent Principles

The following insights and corresponding design principles are extracted from the human centred research process undertaken for this project: part 1: Environment scan of existing grassroots models of seniors supportive living; part 2: Phone interviews; part 3: Site visits and observation; part 4: Analysis and narrative assembly.

The following eight principles are a distillation of what these user-innovators see as key ingredients to aging in place and reducing senior social isolation. They are meant to be used as guidelines to help in the future design of senior supportive living services, as they align directly with the needs of seniors who are attempting to forge new ways of living in the community.

1. PARTICIPATORY BY DESIGN

Meaning and purpose are often taken away from seniors. Being a 'valued member' of the community is desired in spirit and action. Doing things together creates meaning and alleviates social isolation. This includes active choice and retaining control over the decisions that affect their lives.

Building and maintaining senior social living initiatives is seen as a form of mental engagement, that in itself supports aging in place and reduces social isolation

Design Principle: Create opportunities for seniors to design, build and run their own communities.

2. FLUIDITY / FLEXIBILITY

Seniors have a continuum of needs, which can shift back and forth, in a rapid or slow fashion. Seniors are also not a homogenous group, varying significantly regarding values, needs, desires, and abilities.

Grassroots models respond to the changing needs of seniors in their community. They have flexible mandates that allow them to adjust the type and intensity of support offerings. Core services also reflect the specific health and social needs of the residents, as well as characteristics of the surrounding community.

Design principle: Be flexible; allow for the maximum amount of local customization.

3. DECENTRALIZED NETWORKS OF CARE

Senior social living models emphasize a decentralized approach to 'caring' and disperses it amongst the community, thereby strengthening its bonds. It also provides a more extensive safety net for vulnerable seniors as there are more people to keep their eyes and ears open for changes in status.

This also has a system effect of normalizing relationships with adult children and turn them back into 'being' relationships instead of 'doing' relationships, which turn children into caregivers and increases burnout.

Design Principle: Create the mechanisms that allow neighbours to look out for one another

4. LEVERAGE EXISTING RESOURCES

Make use of existing community assets. This includes making use of natural densities of seniors living in the same geographic location (economies of scale; social capital); making use of existing housing stock and community spaces (cost savings), and community services with mandates to serve seniors (increased services).

It also includes reaching out to younger seniors in the community who have the capacity to volunteer. Volunteerism is a mutually reinforcing system that gives support to those in need; an opportunity to give back and feel valued; and a channel for building stronger community bonds.

Design Principle: Build a network of support using existing community assets when gaps in publically available services exist.

5. SYSTEM NAVIGATION

Health care goes beyond the physical. Building services that help seniors connect with services that address the social determinants of health. Many seniors are unaware of what is available; facilitating access through information exchanges, social networking and transportation will help seniors remain able to live independently for a more extended period.

Design Principle: Act as a connection point that increases access to services and information.

6. FOCUS ON RELATIONSHIPS

Building strong relationships, over time, increases chances that seniors are more likely to reach out before a crisis hits. It is not just about “services offered”, but about depth of relationship.

Design Principle: Ensure seniors know they have somewhere to go, and someone to reach out to.

7. CASUAL SOCIAL INTERACTION

The design of physical space can encourage impromptu engagement and casual encounters. Incorporating casual spaces for social interaction helps with community building, trust building and monitoring of health and/or emotional status. Neighbours and health providers are able to see emergent issues before they become a problem. In cases where there are embedded providers, they are ‘a part of’ the community, instead of separate. Office space is embedded with shared areas, not separated in a closed door office.

Design Principle: Create spaces for casual social interaction and encourage residents to take ownership over the use of space.

8. INTELLECTUAL STIMULATION

Staying mentally engaged was seen as a way to stay vibrant and was closely linked to preventing the kind of decline that leads to institutionalization. Many senior-innovators expressed sadness that seniors are characterized as being mentally incompetent and unable to learn new things or participate meaningfully in the community. Creating opportunities to flex this muscle provides a sense of worth and value, and is a preventative measure for staying out of long-term care.

Design Principle: Promote self-initiated lifelong learning programs and encourage seniors to share their wisdom and experience.

Redefining Old Age

As I visited with the seniors in these communities, I repeatedly heard about the need to reimagine the cultural narratives about what it means to be an 'old person'. Many felt current ones were out of touch and out of date with the actual experience. One person said that they "were still the same person, just housed in an older body", and resented being seen as slow or incapable of contributing any value to her community. Another spoke of 'elder wisdom' and the knowledge that has been accumulated over years of life that is discounted in society. They wanted it to be known and valued; they wanted to share it.

To many of the seniors I spoke with there is a dearth of opportunities for seniors to participate in venues where their wisdom is valued. They wanted more opportunity to contribute to change, to the processes of community life, and to political discourse.

These ideas about redefining what it means to grow old were a central theme, in particular in the younger seniors at Harbourside and WHIM. They called for a reframing - and not just at the societal level, but at the individual level as well. For them, the stories we tell ourselves about being frail or 'not as sharp as I used to be' contributed significantly to the impulse to participate, which through this research, we've learned is a key ingredient to aging in place and reducing social isolation.

The lead users who built these new models of senior social living are not content to accept the status quo. And instead of waiting for other people to figure it out, they are simply doing it for themselves. According to Andrew Moore, founding member of Harbourside Cohousing:

"In the 1960's we revolutionized what it meant to be young, and now we want to revolutionize what it means to grow old. It wasn't just sex, drugs and rock and roll – it was the feminist movement, it was civil rights. Community organization ushered in profound societal changes."

"[With cohousing] you are harnessing the energy of the group – which saves you money and gives them life. It's a win-win. It saves the province billions by having seniors look after themselves, and look after each other. We are shifting the idea of seniors from being a needy group, to one that has extraordinary resources."

Bedney, Goldberg, and Josephson in their 2010 report "Aging in Place in Naturally Occurring Retirement Communities: Transforming Aging Through Supportive Service Programs" put it another way:

"NORC SSP also provides a unique opportunity for older adults and aging service providers to rewrite cultural perceptions of aging and promote images of aging and older adults that shatters the old frail weak and vulnerable and that create a new image of older adults capable of controlling their own destinies given the proper resources."

The need to counter our idea of what seniors are capable of seems to be a fundamental building block to creating new, more sustainable models of supportive living in the future. These lead users are articulating what being old can look like if given the opportunity to self-define and self-organize. For systems looking at greying population, self-determination may well hold the key for more efficient and effective models of care delivery.

NEXT STEPS / FUTURE RESEARCH

The research contained herein, although detailed, is only a small sampling of how these types of grassroots models function and the role they may play in helping seniors age well in community. Future research might consider including site visits to more models, paying particular attention to including initiatives that serve diverse backgrounds - including broader socio-economic, rural vs. urban, gender and cultural representation.

It would also be useful to track how well these initiatives develop over time as the communities age, and how that might affect their ability to retain a sense of agency and independence, as well as to keep costs down.

Lastly, it would also be beneficial to evaluate these initiatives based on health system utilization; potential indicators being rates of emergency department usage, calls to 911, premature entrance into long term care facilities, and rates of social isolation.

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Appendix A - Phone Interview Guide

Senior Social Living: Principles for Aging Well in Community : Interview Guide

The 'Senior Social Living' projects seeks to describe the strategies that grassroots models of seniors supportive living are using to reduce social isolation and enable aging in place, and asks what the health system might do to better integrate with these initiatives.

There will be an initial phone interview with participants, followed by an in-person interview that will be audiorecorded. Photographs of the program will be taken, with permission of residents, in order to build a multimedia case study that can be widely shared. We are hoping to visit one site for each of the four models we are documenting: senior cohousing, the village model, naturally occurring retirement communities, and homesharing initiatives.

Key research questions:

- What are the key 'ingredients' at play to reduce social isolation and enable aging in place?
- What was instrumental in getting these initiatives off the ground?
- What are the major barriers to sustaining the initiatives?

Phone Interview Questions:

About

1. Can you describe your living arrangement / model?
2. What was the impetus to get this started?

Support services

3. What supportive living services are available?
4. Who delivers and organizes/coordinates them?
5. Are there other activities that are not considered formal 'supportive services' but are helpful to aging in place nonetheless?

Social

6. Can you describe the community?
7. What makes this community work / survive / thrive?
8. How important is it that residents are like-minded? How is 'difference' negotiated?
9. What are the biggest benefits and challenges of living more communally?
10. Does this environment help reduce 'social isolation'?

Decision-Making

11. Can you describe the decision-making process of the group?
12. Do you have a say in programming and staffing decisions?
13. How are conflicts resolved?
14. What are its benefits and/or drawbacks to this model of governance?

Health Care

15. What level of health care support is currently needed by residents?
16. If there are residents who need a higher level of care, how is that care managed?
17. How is the community planning to care for the health of its members as they age?

Funding & Costs

18. What costs are associated with living here?
19. Is this an affordable option for you? How do you pay for living here?
20. Are there any subsidies available to you or your group?
21. If yes, what are the criteria to qualify for the funding?

Partnerships

22. Does your group hold any formal partnerships with outside organizations?
(government agencies, non-profit or community groups)
23. What are the benefits or drawbacks to these partnership?

Enablers / Barriers

24. Was there anything instrumental in getting this initiative off the ground?
25. What was the most difficult part of getting this started?
26. Are there any barriers you face in sustaining the initiative?
27. Are there any policies that have helped or hindered your group's success?

Aging in Place

28. What are the key 'ingredients' here that are helping seniors age in place?
29. Is there anything about the physical infrastructure that is conducive to aging in place?
30. What is the best and worst part of living here?

Appendix B - User Experience Interview Guide

User Experience Interview Questions

1. Can you describe what it's like to live here?
2. What was your living situation like before you moved here?
3. Were you satisfied? Lonely?
4. When and how did you know that this is what you needed?
5. Did you consider any alternatives? Why did you not choose them?
6. What costs are involved in living here?
7. Is this an affordable and sustainable option for you?
8. Was downsizing a necessity?
9. How are financial costs managed? Do you share costs or pool resources?
10. Does living here meet the expectations that you had?
11. What compromises have you had to make? Did you have to give up anything?
12. Tell me about navigating togetherness and privacy. What is required from an individual to live in a shared and communal environment?
13. How is conflict resolved? How do you foster 'open communication'?
14. What type of person best suits this living arrangement? Is this type of arrangement especially appealing for one gender or another?
15. What is the hardest part about living in community? What is the best part?
16. Do you consider living here part of a plan to 'age in place'?
17. What makes this environment suitable for aging - from a physical, social, and psychological perspective?
18. Are there people you can depend on if you really need it? How do they support you?
19. Do you have in plan in place for when you might need a higher level of health care supports?
20. Would you be able to stay here if you developed physical and cognitive disabilities?
21. Where would you go if you had to leave?
22. Does living here help with the problem of senior social isolation?
23. As you age, what is needed in a 'home'?
24. Is there anything about the generation of seniors coming of age now, the boomers, which is enabling this sort of aging in place initiative?
30. What does it take to live in this type of arrangement?

Appendix C - Multimedia Appendix

1. Audio documentary with Beverly Suak at Women's Housing Initiative Manitoba
The file name of this sound file is "HOMESHARING_Bev.aif"

2. Audio documentary with Katherine Lowery at Women's Housing Initiative Manitoba
The file name of this sound file is "HOMESHARING_Katherine.aif"

3. Audio documentary with Margaret Critlow at Harbourside Cohousing
The file name of this sound file is "COHOUSING_Margaret.aif"

4. Audio documentary with Bob and Arlene Stamp at Harbourside Cohousing
The file name of this sound file is "HOMESHARING_Bev.AIF"

5. Audio documentary with Helen Baker at Co-op Village NORC
The file name of this sound file is "NORC_Helen.aif"

6. Audio documentary with Betty Davis at Verde Valley Caregivers Coalition
The file name of this sound file is "VIRTUAL VILLAGE_Betty.aif"